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Guidance on the support pathway for people with a limb amputation

(and trialling a prosthesis)

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The guidance is to be reviewed in 2030.

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Conflict of interest

icare (Lifetime Care and Support Scheme and Workers Insurance) funded the development of this guidance. The project lead, Dr Sue Lukersmith, is an independent guideline methodologist and developer. Dr Lukersmith was contracted to develop the methods, undertake the research, facilitate the working party and nominal group methods, write the draft, and revise and finalise the guidance. icare staff reviewed the draft and provided feedback for consideration along with the working party members, and national and international peer reviewers.

All working party participants signed a declaration of any real or perceived conflict of interest, collected at the first working party meeting. icare staff involved in the working party declared potential perceived relationship or financial conflicts as employees of a professional association working for their interests. Three working party members declared a relationship or financial connection with importers and suppliers of prosthetic componentry (either as a business owner or employee of such a company). None of these declarations were considered an actual conflict of interest, nor did they compete with the consensus approach for topic generation and decision-making for recommendations developed by the working party. Dr Lukersmith drafted the guidance, which further minimised any potential for conflict of interest.

The working party members did not receive any remuneration from icare for their time. Some working party members were employed by organisations (e.g. government, consumer representative organisation, professional association) and were paid by that organisation for their time. There was no payment for time to working party members who were self-employed, or to icare participants of either of the schemes involved.

icare is not a provider of support services and the guidance is freely available on the internet.

Acknowledgments

All working party members are listed on page 3. icare and Dr Lukersmith would like to thank the working party members for their time, so willingly sharing their knowledge and contributing to the development of the guidance. The working party members were involved in identifying appropriately qualified and experienced external reviewers for the draft and revisions, including people with lived experience. We wish to thank the 10 external reviewers listed in Appendix 1 from Australia and internationally, who kindly gave of their time, reviewed the draft guidance and provided feedback.

We would also like to thank the people with lived experience listed in Appendix 2, for their review of the limb prosthesis maintenance information sheet.

Contents

Foreword

After bilateral below knee amputations, leaving inpatient rehabilitation and returning home to try and find a new normal, can be very scary, intimidating, daunting, tiring and an emotional roller coaster.

What I found really helpful was having the support from the same case manager throughout. My case manager co-ordinated the services I needed from health professionals, access to the resources as well as assisted me with realistic expectations.

Also having a good working/communication style with your prosthetist is invaluable, as you will need to explain how your prosthesis “feels”. This enables a comfortable and high functioning personalised fit of your prosthesis.

Having the support through all of the phases after an amputation is a crucial part of the healing process to creating routine and rhythm with daily activities. The support workers both paid and unpaid, family, friends and co-workers all help you get through days when you really feel and think that you just CAN’T cope and it’s ALL too much.

The guidance document is extensive and patient/individual focussed.

I encourage you to share the guidance as much as possible. The timing of support and a multi- disciplinary approach is essential. The resources and advice contained in it is important for many health care professionals attending amputees.

There are also useful resources and links in the guidance which are helpful for the person with a limb amputation. Some of the topics, the language, the extent of the information and the many references may be a little daunting for some people, but others like myself will be excited by the content.

Elizabeth Ellen Cass
Lived Experience

Executive summary

The guidance concerns adults and young people who have experienced a traumatic injury, because of a motor vehicle crash or work-related injury, resulting in limb amputation, and who are eligible under the NSW injury compensation schemes of Lifetime Care and Support Scheme or Workers Insurance. The guidance was developed for use as part of the overall planning for people who are eligible in the icare schemes.

The support pathway in this guidance relates to the period after amputation and following discharge from inpatient rehabilitation or hospital. The guidance describes the pathway and supports the person may need.

The guidance aims, in the first instance, to provide direction for action for all involved in the pathway. While the guidance focus is on all professionals and organisations involved in the support pathway, the guidance also assists the person with the amputation, their family, carers and support workers. While not specifically developed for people who experience limb amputation because of other health conditions (e.g. vascular disease), the guidance, or some sections of it, could be relevant to these people, or people whose services and support are funded through other social insurance schemes.

The guidance provides recommendations and best practice notes based on all relevant sources of scientific knowledge (experimental and observational research, context, expert and experiential knowledge of those with lived experience of amputation). The topics range from the support pathway facilitators and barriers, to connected health issues, co-occurring health conditions. Resources have been developed or identified to support the use of the guidance and includes information and tip sheets, links to screening tools, information and strategies for both health and rehabilitation professionals and the person with the amputation and their family.

1. Background

The Guidance on the support pathway for with a limb amputation (and trialling a prosthesis) was developed as a joint project by two schemes within icare (Insurance & Care NSW)—the Lifetime Care and Support Scheme, and Workers Insurance. icare is a public financial corporation governed by an independent Board of Directors. icare supports the provision of treatment, rehabilitation and support services to the people of New South Wales (NSW), Australia. icare has the responsibility to support the long-term and lifelong needs of people who have serious injuries that occur either as a result of a motor vehicle crash or in the workplace.

The guidance was developed for use as part of the overall planning for people who are eligible in the icare schemes who have experienced limb amputation following injury. It covers the support pathway that begins after the acute phase, when the person has undergone an amputation and been discharged from inpatient rehabilitation or hospital.

Because the guidance covers a complex, community-based and contextually dependent topic, it was developed using adapted guideline methodology. Refer to Section 6.1 for an overview of the methods used.

2. Aim and scope of the guidance

The aim of the guidance is to inform, guide and assist those involved in the support pathway for a person with a limb amputation related to a traumatic injury who needs a prosthetic limb intervention and/or services.

The support pathway in this guidance relates to the period after amputation and following discharge from inpatient rehabilitation or hospital. The guidance describes the pathway and supports the person may need. The guidance aims, in the first instance, to provide direction for action for all involved in the pathway, including health and rehabilitation professionals, service providers, funders of prosthetic devices and rehabilitation services, and insurance scheme regulators.

While the guidance focus is on all professionals and organisations involved in the support pathway, the guidance also assists the person with the amputation, their family, carers and support workers. Some sections of the guidance, such as tips on pain management and limb prosthesis maintenance, are written specifically for people with a limb amputation.

The guidance is not a clinical guideline for a specific health professional discipline. The guidance provides evidence-based information and recommendations. The perspective adopted for the guidance was holistic and multidisciplinary for all intended users. The topics covered in the guidance are those considered relevant to the support pathway, which were identified by preliminary research and feedback from those with lived experience and the working party (refer to Section 6 Guidance development).

The guidance concerns interventions or services specifically related to people requiring prosthetic limbs; it does not cover interventions or services for those requiring orthotics.

3. Population and health condition

The guidance concerns adults and young people who have experienced a traumatic injury, because of a motor vehicle crash or work-related injury, resulting in limb amputation, and who are eligible under the NSW injury compensation schemes of Lifetime Care and Support or Workers Insurance.

While not specifically developed for people who experience limb amputation because of other health conditions (e.g. vascular disease, cancer, osteomyelitis, congenital anomalies), the guidance, or some sections of it, could be relevant to these people, as a limb amputation is a traumatic experience for any person. The guidance, or some sections, may also be relevant to people whose services and support are funded through other social insurance schemes.

4. Intended users

The intended users for the guidance in the first instance are health and rehabilitation professionals (including rehabilitation physicians, medical practitioners, nurses and allied health professionals, prosthetists, and prosthetic technicians), service providers, funders of prostheses and rehabilitation services (e.g. insurers), and insurance scheme regulators (e.g. the State Insurance Regulatory Authority [SIRA]). The guidance also provides information that can be empowering for the person with an amputation, their family and carers, whether they access all or only parts of the guidance.

5. Use of the guidance

The guidance is intended to inform and guide the user. The guidance does not replace the need for education, supervision or judgment, and careful consideration of the context of the person with the limb amputation. The guidance complements but does not replace process or procedural guidelines, or guidelines relating to policy or statutory obligations.

Throughout the guidance, there are recommendations (typically indicating a 'must' or 'should' action), best practice notes (indicating 'optimal' actions), lists of resources (blue colour for the person and teal for health professionals) and tools, definitions, and links to relevant online resources. Section 14 includes resources for the person with an amputation and health professionals. The guidance does not attempt to provide the only, nor all possible, resources and tools that can be used for the best practice care pathway for people with an amputation.

6. Guidance development

The topic and issues covered by this guidance are complex and concern the real world rather than controlled clinical settings. The scientific knowledge used to inform the appropriate content of this guidance was obtained from all relevant sources: experimental and observational research evidence (research from the literature searches); contextual knowledge (e.g. demographics, systems, history); expert knowledge (formal or tacit knowledge from expert health and rehabilitation professionals and funders); and experiential knowledge (knowledge gained through lived experience, including from people with an amputation and service users, and their families and advocates) [1-5].

6.1 Overview of methods

Mixed research methods were used to develop this guidance. Guideline development involved two stages:

Preparatory stage

- A scoping review of national and international rehabilitation and care pathway approaches and guidelines
- Retrospective file reviews of a sample of 20 icare participants injured in the last 5 years
- Semi-structured one-to-one interviews with 15 people with lived experience of amputation (who were participants of Lifetime Care and Support or Workers Insurance, or Workers Care)
- Semi-structured interviews with 14 sector stakeholders, including service providers, by an independent researcher
- Insurer consultation.

Development stage

- Consultation with people with lived experience and advocates throughout the guideline development
- Multiple systematic searches of peer-reviewed journal databases for research literature on each topic. The literature was searched from 2010 to 2020; literature was assessed for relevance (over 300 research papers, guidelines and reports) and subsequently for the quality of the research.
- A working party of 23 experts including those with lived experience, who met eight times (for a total of 28 hours) over 10 months to develop recommendations and consensus using a facilitated nominal group technique
- Knowledge, documents and reports from reputable key organisational websites (national and international)
- Several rounds of drafting the document, including revision after critical review by the members of the working party, followed by another round of critical review by national and international expert peer reviewers and people with lived experience.

6.2 *Grading recommendations*

The recommendations included in this guidance are based on information from all relevant sources of scientific knowledge on each topic. A grade for each recommendation was determined using the Australian National Health and Medical Research Council (NHMRC) matrix and grading system [6, 7].

Consensus-based recommendations were developed using the nominal group technique in the working party meetings [8]. Given the complexity of the topics, for some recommendations the NHMRC grading system was adapted to conservatively incorporate qualitative research. Single case studies were not included in the grading of recommendations. Refer to Table 1 for descriptions of the grades applied to recommendations.

Table 1 Grade of recommendation

Grade	Description
A	Body of evidence can be trusted to guide practice. • One or more level I or several level II studies with low risk of bias, and all studies are consistent or inconsistency can be explained • Clinical impact is very large • Populations studied in the body of evidence are similar to the guidance population • Applicable to the Australian health care context with few caveats
B	Body of evidence can be trusted to guide practice in most situations. • One or two level II studies with low risk of bias, or a systematic review or multiple level II studies with low risk of bias, with most studies consistent or inconsistencies can be explained • Clinical impact is substantial • Populations studied in the body of evidence are similar to the guidance population • Applicable to the Australian health care context with few caveats
B^{Q}	Body of evidence can be trusted to guide practice in most situations. • As above for quantitative studies • Qualitative studies included in the body of evidence; one or more qualitative studies of high quality and rigour (credibility, transferability, dependability, conformability)
C	Body of evidence provides some support for recommendation(s); however, care should be taken in its application to individual clinical and organisational circumstances. • One or two level II studies with low risk of bias, or level I or II studies with a moderate risk of bias • Some inconsistency reflecting some uncertainty • Clinical impact is moderate • Populations studied in the body of evidence differ from the guideline population, but it is sensible to apply the evidence to the guidance population • Applicable to the Australian health care context with some caveats
C^{Q}	Body of evidence provides some support for recommendation(s); however, care should be taken in its application to individual clinical and organisational circumstances. • As above for quantitative studies • Qualitative studies included in the body of evidence; one or more qualitative studies of high quality and rigour (credibility, transferability, dependability, conformability)
D	Body of evidence is weak and recommendation must be applied with caution. • Level IV studies, or level I to II studies or systematic reviews with a high risk of bias • Evidence is inconsistent • Clinical impact is slight • Populations studied in the body of evidence differ from the guideline population, and hard to judge whether it is sensible to apply evidence to the guidance population
Consensus	Consensus-based recommendation • A systematic literature search was conducted. The recommendation was developed using the discovery and observational research available, plus contextual, expert and experiential knowledge to reach a consensus on the recommendation.

6.3 *Framework and approach*

The guidance is informed by the following international frameworks and underlying practice concepts that underpin evidence-based and best practice person-centred perspectives and approaches:

- The role of health literacy, knowledge and social determinants to the person's empowerment and health outcomes [5, 9-11]
- A biopsychosocial perspective of health as articulated in the World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF) [12]. This is the contemporary perspective of health disability and functioning, and was developed through international consensus using elements of both the social and medical perspectives of health.
- The United Nations Convention on the Rights of Persons with Disabilities [13]
- Person-centredness and person-centred approaches [14-18]. This is different from patient-centred or client-centred. The language in the latter two approaches emphasise the relationship. On the other hand, person-centred acknowledges the person (not position), and the need for empowerment, respect, shared decision making, choice and control.
- WHO framework and principles of integrated care and social supports [19, 20]
- Post-injury planning approach using the icare My Plan toolkit [15].

7. The support pathway

There are numerous personal and environmental factors in any person's life that influence their functioning in terms of their body, activities and participation in life roles. Each adult or young person's recovery and outcomes from a traumatic injury resulting in limb amputation will be different depending on these contextual factors. The nature of the injury and amputation is just one contributor to the situation.

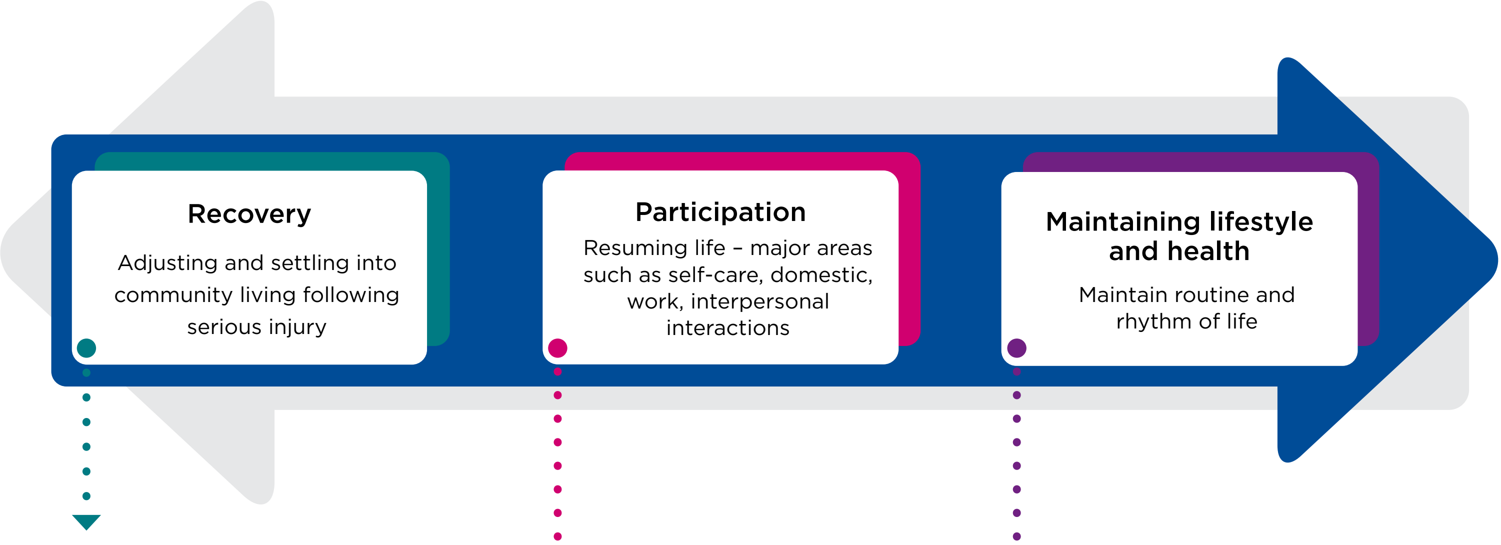
Personal factors are the particular background of an individual's life and living, such as gender; age; social background; education; personal characteristics such as coping style, habits, attitude and motivation; their health before the injury; and the informal (unpaid) supports available to them. Key learnings from the research and the biopsychosocial model of functioning (ICF), show that these factors critically influence the person's progress and outcomes. These contextual factors can be a barrier and hinder progress, or they can be a facilitator and positively influence the person's functioning and progress along the pathway [12, 21, 22].

Environmental factors arise from the person's physical, social and attitudinal environment. Some of the environmental factors influencing the person's progress may relate to the 'system' (e.g. Medicare, Workers Insurance, Lifetime Care and Support, National Disability Insurance Scheme [NDIS]), including the policies and structures for funding treatment, rehabilitation and care; the range and type of services provided; the attitude and approach of organisations and service providers; the timing of services, products and technology; and the physical environment (natural and built).

The guidance on the support pathway is informed by the research evidence, and the working party members' contextual, expert and experiential knowledge [1, 2, 23]. The information, recommendations and best practice notes in the guidance indicate the most appropriate approach and supports that should be provided. However, people's needs, and the context and timing of support will vary. Subsequent sections describing the pathway provide a **general** description of the person's context, what the issues and concerns might be at various times after the amputation, and the services and supports that facilitate progress.

The support pathway is adapted from the My Plan toolkit [15]. The pathway comprises three phases: Recovery, Participation and Maintaining lifestyle and health (refer to Figure 1). A person may experience a life event (e.g. becoming a parent, changing jobs, experiencing a co-occurring health condition) that changes the supports they require and so may move between phases in either direction.

Figure 1 Support pathway phases



Recovery phase

'Recovery' refers to the phase when the person is adjusting and settling into community living after the traumatic injury and amputation. The person is discharged from inpatient rehabilitation or hospital, and will continue with medical and rehabilitation treatments and therapy as an outpatient. Their focus is on minimising physical impairments and limitations to their mobility and performance of self-care activities, and receiving support to help them and their family (including their partner) adjust to their changed circumstances and enhance their psychosocial wellbeing. Goal-setting and planning for services and support for resuming life is relevant to funding and icare.

The recovery phase refers to the time when the person has returned home, although it may be interspersed with re-admission to hospital or inpatient rehabilitation. This occurs if, for example, there are complications (e.g. multiple operations or attempts to salvage the limb), multiple amputations (e.g. the person has both upper and lower limb amputations), or if the upper limb amputation is to the person's dominant arm.

Participation phase

The person will move into the 'Participation' phase as they progress. Some rehabilitation treatments and therapy may continue, but the focus in this phase is on the person's activities, participation, resuming all their roles in life and their continued psychosocial wellbeing. In this second phase, the person will plan and resume the same and/or different activities, and their participation in life at home and in the community. Goals may continue to focus on their mobility, self-care (e.g. dressing), domestic tasks (e.g. cooking or gardening) and using transport (e.g. returning to driving, using public transport), but also roles in major life areas such as education, returning to work/employment, recreation/leisure, community and social life.

Maintaining lifestyle and health phase

The third phase, 'Maintaining lifestyle and health', is when life activities, roles and supports are stable. The person (and their family) continue to maintain their lifestyle and participation without need for major changes to their support services and equipment. In this last phase, the person has settled into the routine and rhythm of life, although they still perform activities necessary to maintain their wellbeing and use of the prosthesis, such as attending their general practitioner (GP) for a general review and their prosthetist for prosthetic maintenance and repairs.

In the following sections we provide information, guidance, best practices notes, and resources and tools for facilitators in the support pathway (refer to Section 8), connected health issues (refer to Section 9) and co-occurring health conditions (refer to Section 10). Adopting these evidence-based best practice approaches to the person and their family optimises their physical, psychosocial and quality of life outcomes [22, 24-26].

8. Support pathway facilitators and barriers

In this section, we focus on factors that are fundamental to and key facilitators for the person's progress along the support pathway, or which, if action is not taken, can create a barrier. We have used information from the research evidence, and knowledge from people with lived experience and health and rehabilitation professionals to identify the best approaches and actions.

These factors should be considered by all those involved in the support pathway, including health and rehabilitation professionals (including rehabilitation physicians, medical practitioners, nurses and allied health professionals, prosthetists, and prosthetic technicians), service providers, funders of prosthetic devices and rehabilitation services (e.g. insurers), and insurance scheme regulators.

8.1 Integrating and coordinating services and supports

Research evidence reinforces that a fundamental requirement for effectiveness of treatment, rehabilitation and health care is that services and supports are integrated and coordinated [27-31]. To support the integration and coordination of services and supports, responsibility for monitoring the person's progress across all services and along the pathway should be assigned to a single person, before or early after the amputation.

Integration and coordination of the services and supports for a person who is traumatically injured and under a personal injury insurance scheme may be facilitated by people in different roles. These are:

- community-based case manager (external case manager or rehabilitation case manager) working at a private, public or not-for-profit health and social service organisation, funded by the person's insurer
- community living facilitator or rehabilitation case manager working at the social insurance agency (e.g. icare NSW, within schemes such as Workers Care, or Lifetime Care and Support)
- case manager working at the worker's insurance funding organisation (e.g. EML, GIO, Allianz)
- claims advisor working at the compulsory motor vehicle third party (CTP) injury insurance funding organisation.

Refer to the glossary for definitions of these roles. People working in these roles may have different titles in other social insurance schemes.

The guidance recommends that an external (or rehabilitation) case manager is engaged by the social insurance agency (funder or funder representative) as early as possible following injury, but certainly at the point of entry into the specific funding scheme.

	Recommendations	Grade
1	Funders must ensure a case manager is engaged as early as possible following injury and certainly at the point of entry into the funding scheme (Lifetime Care, Workers Care, Workers Insurance, CTP Care or other social insurance agency) to support the person with setting their goals and navigating the system, and facilitate the coordination of their supports. In Workers Insurance and CTP Care, the case manager is external to the insurers. In Lifetime Care and Support, Workers Care, the case manager may be an employee.	Consensus
2	The person's general practitioner (GP) should receive discharge information, and should be involved and a part of the multidisciplinary team from the time of the injury. The case manager is responsible for facilitating the link to the GP if this has not already occurred.	Consensus

8.2 *Additional considerations and planning after early discharge from hospital or inpatient rehabilitation*

When the person is discharged early from inpatient rehabilitation or hospital, care should be taken to ensure that the person is not disadvantaged, and that plans are established. Potential concerns and support services that are likely to be affected by an earlier discharge include:

- timely access to the health professionals providing treatment and therapy (public or private)
- accessibility and safety in the person's home environment including home modifications
- timely provision of necessary assistive devices and aids for the person's use at home and in the community (e.g. wheelchair, showering aids)
- impacts on home programs when telehealth services are used rather than face-to-face contact
- frequency and duration of treatment and therapy (e.g. if there are barriers due to personal or contextual factors, service availability or access issues)
- the need for transport to and from outpatient services and the person's independence for travelling (public or private, cost)
- access to the necessary range of multidisciplinary services as needed (e.g. waiting lists may be a barrier to progress)
- adequate monitoring of psychosocial concerns
- supports for the person's family, spouse and carers
- barriers to treatment and therapy compliance.

	Recommendation	Grade
3	The person should be discharged from inpatient rehabilitation or hospital only when a support, services and equipment package to meet their needs has been arranged by the health professionals, approved by the funding organisation and made available.	Consensus

8.3 *Person-centred approach and shared decision making*

The evidence for the benefit of person-centred approaches and shared decision making is strong. These approaches are associated with more appropriate care, a better match with the person's needs and preferences, a reduction in misdiagnosis, and greater satisfaction and independence [32-35]. The WHO recommends engaging in shared decision making with the person (and their family, where relevant and when consent is provided) in matters that concern them directly, whether in health, education, rehabilitation or community living [36].

A person-centred approach is when the health professional or service provider listens to and 'hears' and respects the person, and endeavours to understand their experience, individual circumstances and context.

Person-centred approaches enable, and thereby support, the person (and their family) to make their own health care decisions, and to engage with their treatment and therapy [37, 38]. A person-centred approach and shared decision making involve health professionals meaningfully engaging with the person to share information. The health professional must work alongside and tailor the support for the person to enable them to understand the situations and choices they face, so that they can make their own informed decisions. The health professional should consider the best evidence on treatments, and the person's context and individual needs, options and responsibilities, and progress [15, 16, 18].

Best practice note box 1 presents five key messages for members of the multidisciplinary team on adopting a person-centred approach in their practice.

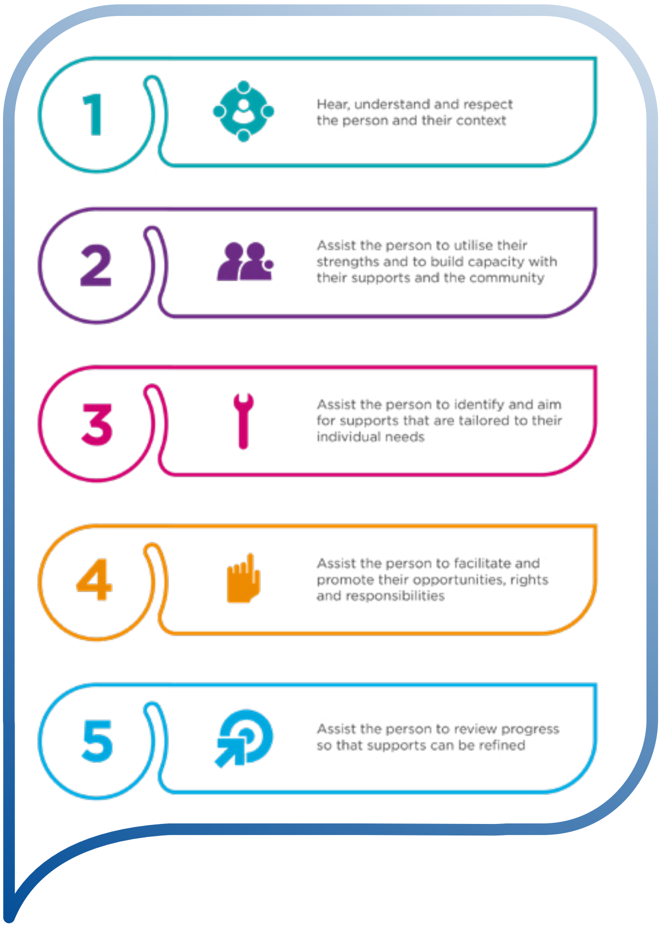
Best practice note—1

A person-centred approach—five key messages for health professionals

1. Hear, understand and respect the person, their context and their decisions.
2. Assist the person to use their strengths and to build capacity with their supports and the community.
3. Assist the person to identify and aim for supports that are tailored to their individual needs.
4. Assist the person to facilitate and promote their opportunities, rights and responsibilities.
5. Assist the person to review their progress so that supports can be refined.

8.4 Person-centred goals

Planning to develop a person-centred goal involves assisting the person with an amputation to work out what is important and a priority for them, develop their goal, and create an action plan with a list of the steps or tasks to be completed to achieve their goal. For example, a common goal for people of working age is to return to work (which may be the same, similar or different work, depending on the situation). The steps for achieving this goal may be returning to driving, using public transport, and ensuring that necessary workplace modifications are in place and any other barriers are removed to enable them to return to work. For someone with a lower limb amputation, their goal is not only walking (mobility) but their independence with transport and moving around the workplace, doing their job. The person's priorities for goals can be very different to what health professionals identify as important [39]. Setting goals, identifying the steps required, and requesting approval for the services and supports the person needs to achieve those goals are a part of person-centred planning and seeking funding. Supports should be provided in all phases of the support pathway to enable this planning approach [26].



The reason for setting person-centred goals is that they are meaningful and understandable to the person, whereas clinically oriented goals established by the health professional for their own work tasks may be less meaningful. Setting person-centred goals can have multiple benefits for rehabilitation and the person's progress along the support pathway. Benefits include helping the person with adjustment to their amputation and their perception of being an active agent and having a degree of control in their own pathway of recovery [40]; enhancing their health literacy and motivation [10]; and enhancing their participation with their own treatment and rehabilitation, and improving outcomes [41]. In particular, people with lower limb amputations perceive setting their own goals as one of the enablers to their community walking [42].

The case manager should be involved as early as possible following a person's injury, certainly at the point of entry into the funding scheme (refer to Recommendation 1). The case manager supports the person with setting their goals. However, setting goals and determining the necessary actions, who performs them, and the necessary services and supports to achieve the goals will also involve the multidisciplinary team.

Best practice note—2

Person-centred goals

The case manager should assist the person to establish person-centred goals and ensure that relevant supports are identified (refer to Recommendation 1 Section 8.1) which states:

Funders must ensure a case manager is engaged as early as possible following the person's injury, certainly at the point of entry into the funding scheme (Lifetime Care and Support, Workers Care, Workers Insurance, CTP Care), to support the person with setting their goals and navigating the system, and to facilitate the coordination of their supports.

Resources—1 Information for healthcare professionals

Setting person-centred goals

People under the Lifetime Care and Support Scheme, Workers Care program develop person-centred goals and articulate the steps and services to achieve those goals in their My Plan
See: www.icare.nsw.gov.au/practitioners-and-providers/healthcare-and-service-providers/planning-with-an-injured-person

In Workers Insurance, the plan is referred to as an Injury Management Plan (IMP)
See: www.icare.nsw.gov.au/employers/employer-obligations/return-to-work-programs/return-to-work-assistance#gref

The Prosthetic Request Form submitted to the funding organisation requires the inclusion of at least one person-centred goal
Refer to Section 13 Resources—Prosthetic Request Form

Limbs4Life also provide some further suggestions for the person on goal setting
See: www.limbs4life.org.au/funding/setting-goals

8.5 Considering what information to provide and when

Understanding and navigating the health care system is important for the person and their family, especially in the first phase of the support pathway. When a person is severely injured, they are suddenly placed in a complex health care system. They must simultaneously adjust to the trauma and changed personal circumstances, and negotiate this complex system. This may be confusing and at times overwhelming. The person (and their family or carer, if available) should be provided with verbal and written information on:

- the health care system
- different health professionals, their roles and responsibilities
- the interface with other systems such as equipment suppliers, social insurance and injury funding systems.

Most people who have experienced trauma and an amputation need time to absorb information. Personal factors such as education and coping style influence the person's adjustment [12, 16, 43]. It is important that all health professionals and other services involved in the support pathway consider the timing and accessibility of the information provided. This applies to general information (e.g. services available), specific information relevant to a treatment or support, and process-related information (e.g. funding approval).

Even if the information is provided, the person or their family may not be able to use the information at that time or recall it later. Information needs to be provided in a person-centred way at the right time for that person (and their family, partner, carer) and possibly more than once. Refer to Section 8.6 for information on health literacy and using the 'teachback' method to aid understanding.

Best practice note—3

Considering what information is provided and when

Information should:

- be available at any phase in the support pathway
- be accessible in a number of ways (verbal, written in easy-to-read formats, visual and by demonstration)
- be adjusted for personal factors such as education and cultural (including language) concerns
- consider the presence of connected or co-occurring health conditions
- be provided in a person-centred way at the right time for that person (and their family, partner, carer) and possibly more than once.

Resources—2

Information for people with a limb amputation

Information for person with a recent limb amputation

- Amputee NSW
  See: www.amputeesnsw.org.au

- HealthShare EnableNSW
  See: www.healthshare.nsw.gov.au/services/enablensw

- Limbs4Life
  See: www.limbs4life.org.au/resources

Understanding the health care system and health professional specialities

See: www.limbs4life.org.au/uploads/resources/Fact-Sheet-1.pdf

- Australian Orthotic Prosthetic Association
  See: www.aopa.org.au/publications/clinical-specialties

Goal setting

- Limbs4Life
  See: www.limbs4life.org.au/funding/setting-goals

8.6 *Health literacy*

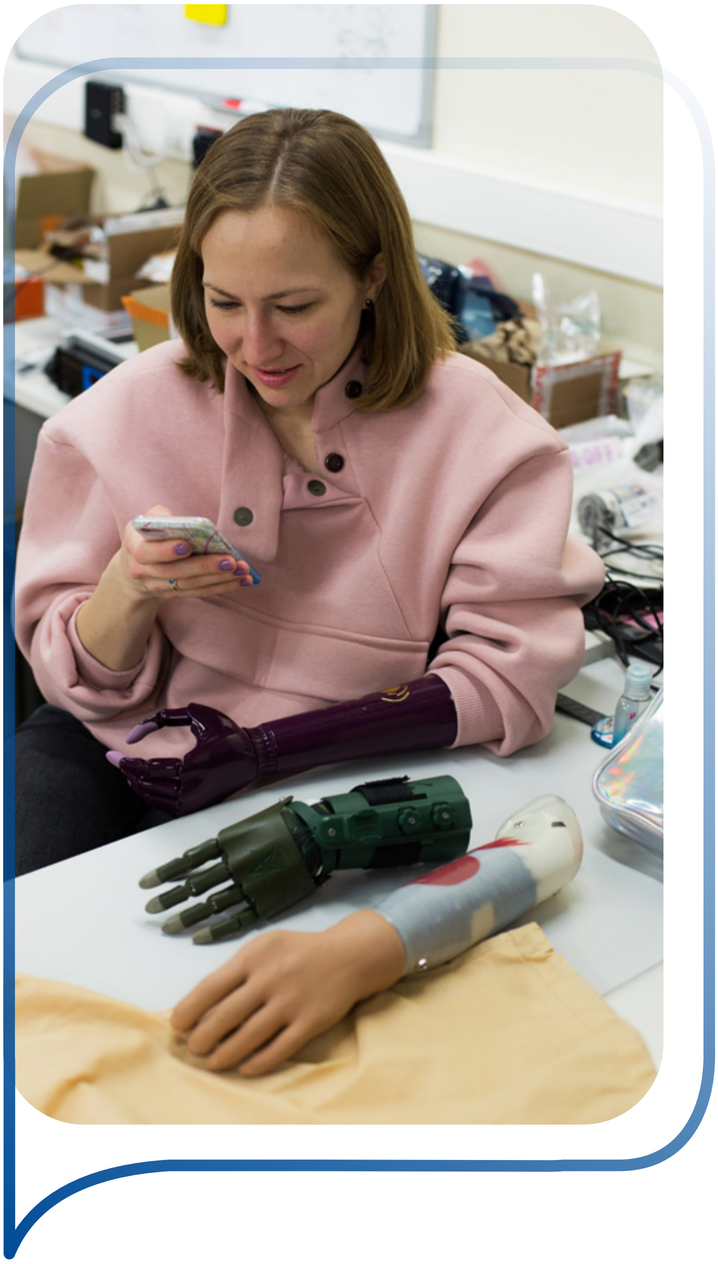
In Australia, more than half (60%) of people have low health literacy [44]. Health literacy is linked to the person's knowledge, motivation and ability to access, and capacity to understand, weigh up and apply health and therapy information. It determines the person's ability to make decisions in everyday life about their health care, what they can do to prevent diseases, and promote their own health to maintain or improve their quality of life, activities and participation [10]. Health literacy empowers the person to engage with their own health [20].

Personal factors such as ethnicity, language, education, age, mental health and motivation influence the person and their skills, and therefore their health literacy. Health literacy is also affected by environmental factors within the whole health system (including public, not-for-profit and private organisations), such as what health information is available, and when, how and by whom it is communicated and made accessible to the person. It is critical that the health information is not only accessible to the person, but easily understood by and applicable to them.

It is also important for health professionals to be person-centred, and to recognise, adapt and facilitate the person's engagement with their own health literacy, including screening to check on their progress (refer to Section 8.9). The multidisciplinary team working with a newly injured person must not assume that the person or their family have all the knowledge and skills they will need for making decisions related to their injury.

To help the person be 'health literate', support can be provided to enable them to:

- access information (seek, find and obtain health information)
- understand the information (comprehend the information)
- appraise the information (interpret, filter, judge and evaluate the health information)
- apply the information (communicate and use the information to make their own decisions around maintaining and improving health) [10].



Everyone involved in the support pathway is responsible for supporting the person's health literacy, including the multidisciplinary team, and the peer support person, advocates and funder who have contextual, expert and experiential knowledge. Best practice is to always use the 'teach-back' method and person-centred approaches to provide health-related information and advice, and to check the person's understanding and ability to weigh up and apply the information. A range of resources are available for the person, organisations and the multidisciplinary team to enhance health literacy (see Resources boxes 3 and 4).

	Recommendation	Grade
4	The health professional should always use the best practice ‘teach-back’ method and person-centred approaches when providing health-related information and advice. See: teachback.org	B

Best practice note—4

Health literacy

The person’s health literacy can be facilitated and supported by everyone involved in the support pathway, but particularly through the multidisciplinary team’s attitude and communication (written, demonstrated and verbal).

Everyone involved has a responsibility to facilitate, support and empower the person by providing education and information about treatment, rehabilitation and care for all aspects of the person’s health, not just the amputation and prosthesis.

Use the ‘teach-back’ method and person-centred approaches as a simple yet effective way to communicate and check understanding.

Resources—3 Information for people with a limb amputation

Health literacy for the person with an amputation and their family

How to get started

Prepare some questions to ask your health professional. Write them down, print them out. It will help you to remember what to ask and the answers. There is a tool you can use to help write your questions but don’t rely only on this.
See: www.healthdirect.gov.au/question-builder (Health Direct Australia)

Getting involved in making decisions that concern you
Ask at least three questions:

1. What are my options?
2. What are the possible benefits and harms of those options?
3. How likely are each of those benefits and harms to happen to me?

See: askshareknow.com.au/ask-questions/overview (Ask Share Know Australia)

Before you get any test, treatment or procedure ask these five questions:

1. Do I really need this test, treatment or procedure?
2. What are the risks?
3. Are there simpler, safer options?
4. What happens if I don’t do anything?
5. What are the costs?

See: www.choosingwisely.org.au/resources/consumers-and-carers/5questions (Choose Wisely Australia)

Resources—4 Information for healthcare professionals

Health literacy for the multidisciplinary team and individual health professionals

Always ‘do with and not for’

Recognising low health literacy

Indicators of low literacy include:

- non-compliance with treatment and rehabilitation
- recurrence of the same problems
- poor medication management
- difficulty making informed health decisions
- over-use, under-use and misuse of the health care system
- over-representation of vulnerable populations in acute care facilities.

When indicators of low health literacy are observed, further assessment is required.

See: www.ceh.org.au/resource-hub/social-determinants-of-health-and-health-literacy
(Centre for Culture, Ethnicity & Health)

Learn about and use the best practice ‘teach-back’ person-centred approach to providing health-related information and advice

The seven key principles of the teach-back method are:

1. Advise the person that the responsibility to explain things clearly is on the health professional or provider.
2. Take bits of information, group them together and check the information you provide.
3. Use plain language.
4. Find out how the person likes to learn (reading, talking, using visuals).
5. Clarify for any misunderstandings, until understanding is achieved.
6. Check the person’s current understanding.
7. Ask the person to explain it back to you in their own words.

See: teachback.org (teach-back group at NSW South Eastern Sydney Local Health District)

For tips on practice and evaluation of the teach-back method, see: teachback.org/tips-for-practice

Resources for the whole organisation on health literacy practice

Health literacy resources for organisations (NSW Clinical Excellence Commission)
See: www.cec.health.nsw.gov.au/improve-quality/teamwork-culture-pcc/person-centred-care/health-literacy

A gap analysis of the organisation’s health literacy capacity using the ‘Ten Attributes of Health Literate Health Care Organisations’ (National Academy of Medicine [USA])
See: nam.edu/perspectives-2012-ten-attributes-of-health-literate-health-care-organizations

Health literacy: taking action to improve safety and quality (Australian Commission on Safety and Quality in Health Care)
See: www.safetyandquality.gov.au/sites/default/files/migrated/Health-Literacy-Taking-action-to-improve-safety-and-quality.pdf

Example of a framework developed for an organisation - *icare Health Literacy Framework V1 - Lifetime Injuries*
See: www.icare.nsw.gov.au/injured-or-ill-people/motor-accident-injuries/guidelines-and-policies

8.7 *Peer support*

Trained peer support is an approach that is based on a shared experience of a health condition (e.g. amputation) and specifically provided to support someone to manage their own health condition. It is based on trust, equality, a shared understanding, respect and mutual empowerment between people in similar situations [45]. There is consistent research evidence, and expert and experiential knowledge of the beneficial impact to the person's recovery of the involvement from a trained peer support person [31, 46-49].

Peer support is known to assist and empower people to manage their health and wellbeing and, in particular, to [26, 45-47, 49-51]:

- emotionally adjust to the amputation
- feel accepted and socially included
- compare experiences
- find new coping strategies
- increase their knowledge through access to information and resources
- improve social skills and re-engage with their communities
- self-manage their condition
- improve their social and psychological wellbeing
- improve their quality of life.

Peer support is most effective between people with the same health condition, but can also be effective between those with other factors in common, such as cultural background, language, religion, age, location, personal values or gender [52, 53].

Referral to a managed peer support program is one of NSW Health's minimum standards of care of the person following amputation (refer to Standard 4 [26]) and recommended by guidelines [24]. The person should be offered the opportunity to access a trained peer support volunteer as early as possible (before the amputation when possible) and throughout the support pathway [24, 26, 54]. Even if the peer support is declined by the person at the time (e.g. as an inpatient), a trained peer support service should be available at any time in the pathway that the person chooses to access it. If face-to-face peer support contact is not possible or limited, virtual contact (similar to telehealth) may be considered [55].

Photo of Khoa Tran (Lifetime Care participant) and Xiaotong Huang (Coordinator – Lifetime Care)

Peer support providers and amputee support groups are an important part of the support system and part of the multidisciplinary team [54]. The information and education that a peer support worker can provide is not necessarily provided by any other multidisciplinary team member [55, 56]. Peer support workers and health professionals provide different types of support and neither can replace the other.

In Australia, peer support programs for people with amputations are currently managed through not-for-profit organisations, which provide access to trained volunteers with lived experience (in some situations, this may be a carer of someone with an amputation). A managed peer support program ensures that peer support workers:

- "are matched to the needs of the individual person (e.g. age, sex, cause of amputation)
- have completed a formal program of training that reinforces strict guidelines and boundaries relating to program policies and procedures for dealing with people in vulnerable situations, support them in the development of skills for communication and listening
- have access to post-visitation debriefing and reporting
- have lived with amputation a minimum of 2–3 years and have adapted to limb loss
- undergo police and reference checks
- agree to abide by the policies and procedures of the program" (p. 17) [26].

	Recommendation	Grade
5	All health care professionals involved should ensure that the person is offered referral to a managed peer support program before the operation to amputate, and after the operation in any or all phases of the support pathway (recovery, participation, maintaining lifestyle and health)	B^Q

Resources—5 Information for healthcare professionals

Trained peer support workers

Trained peer support workers can be accessed by contacting the organisations offering managed peer support programs.

These organisations are:

- Amputees NSW
  See: https://amputeesnsw.org.au/resources/
- Limbs4Life
  See: www.limbs4life.org.au/peer-support

8.8 *Carers and support for carers*

A carer is a person who provides **unpaid** support to a person. The carer is generally a family member, spouse or partner, or friend. A carer may also be referred to as an informal support, caregiver or valued (or significant) other. Most people have a carer in their lives, who provides unpaid support. For a person with an amputation, the support provided by a carer is typically very important. A person may also receive assistance to perform tasks of daily living from a **paid** support worker. For more detailed definitions, refer to the glossary.

Supporting carers is important to both the person with an amputation, and their carer or family. Typically, as carers and the family provide support and assistance to the person, they need to develop new understanding, knowledge and skills. As carers are a key support for the person in their own environment, the carer's attitude, stress, and whether they are coping are important factors for the multidisciplinary team and the person with an amputation to consider [57-60]. The research also suggests that carers who are involved in the person's rehabilitation are likely to experience lower levels of depression [61].

Carers play an important role in the lives of many people with a disability, including people with an amputation. The NSW Carers (Recognition) Act 2010 enacts a Carers Charter which recognises the important role and valuable contribution of carers to the community and to the people they care for [62].

1. Carers make a valuable contribution to the community.
2. Carers' health and wellbeing is important.
3. Carers are diverse and have individual needs within and beyond their caring role.
4. Carers are partners in care.

The important role and contribution that carers make to someone who has an amputation should be acknowledged. Whenever possible and with the consent of the person, involve carers in discussions, planning and decisions affecting the person with the amputation [63].

Research has established the close relationship between the quality of life of the person with an amputation and their carer or spouse. If there is improvement in one person, there is likely to be improvement in the other [64]. The reverse is also the case—increasing levels of anxiety in the person experiencing a traumatic amputation have been shown to increase the anxiety of the carer and vice versa. The research suggests that this is particularly the case when the amputation is a higher-level lower limb amputation [57, 65]. Carers who do not receive help report higher levels of stress [66]. At the same time, higher levels of support provided to carers are associated with higher levels of satisfaction, reduced conflict, and better outcomes, such as mobility, for people with lower limb amputations [58, 60].

These impacts demonstrate how important it is to monitor the carer's health and wellbeing throughout the support pathway. Factors that should be monitored are the carer's capacity to care and take on responsibilities, the duration of care they provide, whether they also have a health condition themselves, and the carer's mental health and physical symptoms [59].

	Recommendations	Grade
6	The health professional should consider the capacity and needs of the carer and refer them to appropriate support services as required, e.g. GP, social worker.	B^Q
7	Any health professional from the multidisciplinary team should explore support options for the carer, and identify any gaps in line with the support needs of the person with an amputation.	Consensus

Resources—6 Information for people with a limb amputation

- The Australian Government Department of Social Services has developed a Carer Gateway which provides information about services and supports available for carers via a website, phone service, service finder and Facebook page—see: www.carergateway.gov.au
- Resources with information on and for people with an amputation, their families and carers are also available from:
- Amputee NSW
  See: www.amputeesnsw.org.au
- Limbs4Life
  See: www.limbs4life.org.au

Resources—7 Information for healthcare professionals

Carer support

Support services

Various organisations offer services to support and sustain carers in their work.

Carers NSW has developed and facilitates programs and resources such as peer support; carer support groups; phone lines for information, support and counselling; fact sheets; education and training; and mentoring and support programs.

Refer to the Carers NSW website—see: www.carersnsw.org.au/advice

Screening for carer strain

The Modified Caregiver Strain Index is a reliable and valid tool to for screening carers for their level of strain. For the tool, references and an explanation, see: www.sralab.org/sites/default/files/2017-07/issue-14.pdf

8.9 *Regular screening*

When a person sustains a traumatic injury, they and their family and health and rehabilitation professionals may focus their attention on the person's physical health and recovery. It is easy for other issues to be missed, which can lead to complications and worse outcomes. It is important to screen for and monitor the person's progress in each phase on the support pathway.

The purpose of screening is to find out whether the person is at risk of developing, or already has, specific issues that require further assessment, intervention or support. Screening is generally brief and does not lead to diagnosis, but it may be used in conjunction with an assessment. An assessment is much more comprehensive and usually involves multiple domains of functioning using standardised tests, observations and interviews, which aids a clinical diagnosis and treatment planning.

For this guidance, we used research evidence, lived experience, and health and rehabilitation professional knowledge to develop a list of red and yellow 'flags'. These flags can be used at any phase on the support pathway for screening the person's progress. The presence of a red flag suggests serious issues, and yellow flags can indicate barriers to the person's recovery or progress. Both red and yellow flags can also indicate the rate of the person's recovery or the severity of current issues, and thereby their outcomes.

Identification of red or yellow flags during screening can be the trigger to initiate or take action with supports (for the person or their family). For example, identifying a red or yellow flag may trigger referral for a specific assessment; provision, cessation or adjustment of treatment; or initiation of different supports and services. The case manager and GP often play a critical role in ongoing monitoring and screening of the person's progress in each phase along the support pathway.

	Recommendations	Grade
8	Members of the multidisciplinary health care team should be aware of, and screen for, red and yellow flags. All multidisciplinary team members have a role in screening.	Consensus

Best practice note—5

Screening for red and yellow flags

Red flags

Red flags* are the signs and symptoms that may indicate serious issues, impairment or pathology to body function or structures, or certain patterns that can have a major impact on the person's progress throughout the pathway phases. Red flags need assessment and services and supports to facilitate change as appropriate.

Red flags in the recovery phase of the pathway are:

- missing therapy appointments and prosthetic review regularly
- issues with wounds, wound care or infection (refer to Section 9.5)
- signs and symptoms of impaired cognitive capacity, particularly if there is a pre-existing learning difficulty or there was concussion at the time of the injury [67, 68]; for example,
  - headaches that won't go away
  - having more trouble than usual with attention
  - poor concentration or memory
  - feeling dizzy, unexpected balance problems
  - more difficulty than usual with making decisions and solving problems
  - feeling vague, slowed or 'foggy'
  - mood swings
  - sensitivity to sounds or lights
  - behaviour or personality change
- psychosocial concerns or psychological trauma, and low quality of life (refer to Section 9.1)
- homelessness
- drug addiction
- pre-existing conditions e.g. diabetes (refer to Section 10.2)
- medication concerns e.g. compliance, prescriptions
- absence of informal support
- presence of more than two yellow flags.

In the next two phases (participation, and maintaining lifestyle and health), the additional red flags are:

- issues with pain management (refer to Section 9.4)
- secondary or connected medical conditions (e.g. low back pain, contralateral joint pain) (refer to Section 9)
- ongoing psychosocial concerns and mental health issues (refer to Section 9.1).

*Red flags in some contexts refer to emergencies within the body. Here, red flags refer to contextual and observed factors that can lead to serious long-term negative impacts.

Best practice note—5

Yellow flags

Yellow flags include psychosocial, personal or environmental factors that may be barriers to recovery and progress, or that may increase the risk of greater long-term disability. Yellow flags in the recovery phase of the pathway are:

- increase or decrease in body weight (refer to Section 8.13)
- low health literacy (refer to Section 8.6)
- limited support network (e.g. informal supports or carer, social network)
- carer (spouse or significant other) is not coping (stressed, depressed or anxious) or there are gaps in the support available (refer to Section 8.8)
- missed routine prosthetic appointments
- not using the prescribed prosthesis
- tendency to avoid independence when and where possible
- general practitioner is not engaged early
- key life events, e.g. death in the family, another accident
- necessary home modifications are not completed
- cultural factors or attitudes that become barriers to independence.

In the next two phases (participation, and maintaining lifestyle and health), additional yellow flags arise when the person:

- has not returned to pre-injury or meaningful activities and roles at a time that may be expected (e.g. work, exercise routine, social activities or their parenting role, or if a self-management routine is not established)
- is not confident and not managing nor navigating rehabilitation and medical requirements independently
- experiences under- or over-expectations of performance (from self, family or others)
- is dissatisfied with or reluctant to use the prosthesis
- has limited psychosocial adjustment to the amputation.

In addition to regular screening for red and yellow flags, the guidance recommends the routine use of tools to check on various aspects of the person's progress. An extensive literature search was conducted to identify standardised and validated tools that were fit for purpose, used with people with an amputation, accessible to anyone (on the internet and available to any health professional or anyone else interested) and free to use, and which took limited time to complete and score. Additional considerations when identifying appropriate tools were the balance of burden and benefit, to the health professionals and the person, between self-reported versus observational tools, and the alignment with existing tool use (e.g. the World Health Organization quality of life assessment [WHOQoL] is used throughout icare).

The guidance recommends use of the following tools:

- two overall functioning tools: one for people with lower limb amputation—Amputee Mobility Predictor (AMP)—and another for people with upper limb amputation—Disabilities of the Arm, Shoulder and Hand (DASH)
- a tool for screening pain—Visual Analogue Scale (VAS)
- two tools for psychosocial concerns—Patient Health Questionnaire (PHQ-2) and Generalized Anxiety Disorder (GAD-2). These can also be accessed as one combined tool—the PHQ-4.
- a tool on quality of life—WHOQoL-BREF.

Any member of the multidisciplinary rehabilitation team, including the general practitioner, can ask the person if they are willing to complete the tools (in particular, the pain, psychosocial and quality of life tools) to check how they are progressing.

Using the recommended screening tools provides a common framework for all people involved in the support pathway, including the person and their family, to understand potential concerns and monitor progress.

The use of these tools for screening and ongoing monitoring throughout the phases of the pathway will establish a baseline of information and contribute to outcome measurement. Health professionals are encouraged to use additional standardised tools to measure specific outcomes relevant to the person's treatment and goals (refer to Section 8.4 Person-centred goals and Section 8.10 Outcome measurement) and not solely rely on those recommended in the guidance.

	Recommendations	Grade
9	The relevant functioning tool (AMP or DASH), pain scale (VAS), psychosocial concerns (PHQ-2 and GAD-2) and quality of life (WHOQoL-BREF) tools should be used with the person in the recovery phase, and, at times, in the participation and maintaining lifestyle and health phases.	Consensus
10	The screening information (or a summary of results), and any change over time, should be discussed with the person and their family, and provided to the multidisciplinary team for assessment or action on supports if required.	Consensus
11	Relevant information from screening should also be forwarded to the funding organisation, and included in the reasoning of requests for assessments, equipment, prosthetic devices and support services.	Consensus
12	If monitoring and screening identifies the presence of red or yellow flags, the screening tools should be used again and at any other relevant time throughout the support pathway.	Consensus
13	Screening of quality of life (WHOQoL-BREF) should continue annually until the person is in the final phase of maintaining lifestyle and health. The case manager should check that this occurs.	Consensus

Resources—8 Information for healthcare professionals

Screening tools for functioning, pain, psychosocial concerns and quality of life

Functioning

Amputee Mobility Predictor (AMP)—for lower limb amputation (39 items)
See: www.physio-pedia.com/Amputee_Mobility_Predictor

The AMP is designed to assess specific tasks in K levels for a person with a lower limb amputation. There is also a bilateral amputation form available on the AMP website.

Disabilities of the Arm, Shoulder and Hand (DASH)—for upper limb amputation (30 items)
See: www.sralab.org/rehabilitation-measures/disabilities-arm-shoulder-and-hand-questionnaire

Pain

Visual Analogue Scale
See: www.physio-pedia.com/Visual_Analogue_Scale

Psychosocial concerns and quality of life

Psychosocial

Patient Health Questionnaire (PHQ-2)
See: www.hiv.uw.edu/page/mental-health-screening/phq-2

Generalized Anxiety Disorder (GAD-2)
See: www.hiv.uw.edu/page/mental-health-screening/gad-2

Both PHQ-2 and GAD-2 combined—the PHQ-4
See: www.capc.org/documents/download/467/

Quality of life

WHOQoL-BREF
See: www.icare.nsw.gov.au/practitioners-and-providers/healthcare-and-service-providers/planning-with-an-injured-person

8.10 Outcome measurement

An outcome measure is a tool to determine a person's progress, using the same method over two or more points in time [69, 70]. The use of outcome measures is important from the perspective of the person, the health professionals and the funder. Patient-reported outcome measures (PROMs) are tools that provide a way of measuring health outcomes from the person's perspective (and therefore are person-centred), rather than health professional's perspective. The use of PROMs provide an important, accurate and standardised way on complex outcomes such as functioning, activities and participation [71-73]. All the tools recommended in section 8.9 to support screening the person are PROMs.

From the perspective of the person with an amputation, their family, and the health professionals and support workers involved, measuring progress and outcomes is helpful for:

- making decisions on treatment and for monitoring change (no change, improvement or deterioration)
- knowing what is and what is not working (for the continuation or cessation of treatment)
- identifying factors that may compromise treatment outcomes (e.g. psychosocial concerns)
- providing feedback to the person on progress towards their goals
- supporting the engagement and collaboration of the person as an agent in their own treatment, rehabilitation and progress (particularly when it is a self-reported outcome measure or one where the person is responsible for measuring things like frequency and time spent on activities).

Measuring outcomes also provides information for the health professionals and funders to make decisions about what needs to be changed with the person's rehabilitation and therapy programs, and the next steps. Outcome measures also support the reasoning behind the type of equipment (including prosthesis), treatment and rehabilitation, community services and supports that are considered reasonable and necessary for the person and their family.

From the funder's perspective, measuring outcomes:

- contributes to greater details and understanding of the person and their context
- provides transparent information that assists with decision-making on planning for the person and funding requests
- provides transparency and supports reasoning for treatment, rehabilitation and care requests
- provides relevant data that is useful at the population level and scheme level.

	Recommendations	Grade
14	Health professionals should use and report on reliable and validated outcome measures as best practice.	A
15	The person who administered the outcome measure is responsible for following up with actions or referrals where indicated, and for providing feedback to the person and other team members, e.g. by phone call or referral.	Consensus

Best practice note—6

Outcome measures

There are numerous tools available to health professionals that are reliable and valid to measure changes in specific factors, progress towards the person's goals and the influence of specific treatments. Measuring outcomes needs to be linked to the person's goals.

There are also simple, standard, real-world outcome measures that can be used, such as frequency, task intensity and time measures (e.g. whether and how frequently the person is capable of independently completing a task per day or per week, the distance walked, or changes in the time taken to complete a routine task). The guidance is not a clinical guideline so does not recommend outcome measures for specific treatments or health professional disciplines.

The guidance recommends screening tools which are all patient reported outcome measures (PROMs) for regular monitoring (refer to Section 8.9 Regular screening) which should be used in conjunction with observation, interview and other standardised or real-world fit-for-purpose outcome measures consistent with the health professional's area of expertise, experience and knowledge of their use.

8.11 Lifelong monitoring

As amputation is a lifelong health condition, the need for ongoing prosthetic review, treatment and therapy, and access to a multidisciplinary team is critical. Although the need for follow-up and support of any person with an amputation is lifelong, the frequency and range of supports will differ over time [54, 74]. The need for prosthesis replacement, repair, modification and adjustments will depend on environmental factors, user activity and physiological changes [75]. The need for support may also change, even if temporarily, with key life events such as the anniversary of the injury or amputation, changes to pain experience, ongoing or new connected health issues, changes to lifestyle (e.g. losing a job, becoming a parent, moving homes), changes in personal circumstances and supports (e.g. death of a carer who provided informal supports), experiencing other health conditions (e.g. diabetes), or further injury. Lifelong counselling and support should be available to the person and their carers as needed, in addition to that provided before and after the amputation [26].

Generally, the person has ongoing contact with the prosthetist for the rest of their life. It is important that contact with other members of the multidisciplinary team is triggered when it needs to be. A case manager, if one is involved, or the prosthetist is responsible for referring the person to other members of the multidisciplinary team if they experience issues requiring assessment, treatment or therapy (refer to Recommendation 22, Section 8.18). Some guidelines suggest that the person with a limb amputation needs an annual multidisciplinary assessment throughout their life [24]. This guidance recommends that the person should maintain regular contact with their GP, at least every 12 months.

	Recommendations	Grade
16	The person should maintain regular contact with their GP, at a minimum every 12 months.	Consensus

8.12 Ageing with an amputation

In this guidance, the focus is on people with a limb amputation as a result of traumatic injury, who are typically under 65 years old. Most people undergoing an amputation have chronic peripheral vascular disease or diabetes and are over 65 years of age [76, 77]. For people with diabetes and chronic peripheral vascular disease, the experience of amputation with further ageing is quite different to the experiences of the target population of the guidance. However, the guidance is informed by research on limb amputation generally, ageing and, in particular, ageing with a disability.

As any person gets older, they must adjust to underlying changes to functioning such as movement, sensory function, cognitive function, immune function and sexuality [78, 79]. The WHO World Report on Ageing and Health draws on the data from the Global Burden of Disease project (2013) and identifies common causes of years of healthy life lost due to disability in people older than 60 years.

The data shows that the greatest burden is from [79]:

- sensory impairments (vision and hearing)
- back and neck pain
- chronic obstructive pulmonary disease
- depressive disorders
- injury related to falls
- diabetes
- dementia
- osteoarthritis.

More than half of older people are affected by co-occurring health conditions, which particularly occur between the ages of 50 and 60 years and in advanced older age [79].

For a person with an amputation, any of these common health conditions in combination with their amputation can have an impact on their functioning as they age. Walking and mobility may be particularly affected if the person has a lower limb amputation.

Like others with existing mobility impairment, a person with lower limb amputation may experience earlier functional loss as they age [36]. People with lower limb amputation are already vulnerable to falling, with up to 50% experiencing a fall every year [80]. People ageing with an amputation can be even more vulnerable to some co-occurring health conditions such as weight increase (refer to Section 8.13), diabetes (refer to Section 10.2) and falls [80]. How people age with an amputation is also influenced by their age at the time of amputation; their context and living situation; their health, fitness and function before the amputation; connected health issues (refer to Section 9) they experience because of the amputation, such as phantom limb pain; and health issues co-occurring at the time of injury (refer to Section 10) [36, 77, 78, 81, 82].

In the longer term, age-related health conditions may influence or complicate the use of the prosthesis. For example, for a person with a high-level amputation (transfemoral versus transtibial), cognitive impairment or depression can make ageing more complicated [74, 82-84]. Across all older amputees, irrespective of the reason for the amputation, the person benefits from rehabilitation, and fitting of a prosthesis results in a better quality of life and the person using their prosthesis every day [74, 76, 83, 85, 86]. Each person should be provided with the same opportunities for prosthetic fitting and trial (if they choose to do so and a multidisciplinary assessment concurs), as well as rehabilitation and supports, irrespective of their age [87-89].

The person needs to be reviewed in their home environment and undertaking their daily activities. It is appropriate for the person to re-engage with a multidisciplinary team including peer support workers early and to seek support to prevent complications (e.g. from falls). After review by the GP, a re-referral to the multidisciplinary team may be needed if the person's contact with the team has lapsed.

	Recommendations	Grade
17	Each person should undergo an individualised multidisciplinary assessment of their potential to use a prosthesis, including the older person with limb amputation.	B^Q
18	Any known age-related risk factors (e.g. sensory impairments, falls, diabetes, dementia, arthritis) should be assessed at times of screening or monitoring, during reviews with the multidisciplinary health professionals, and at the least annually with the GP (refer to Recommendation 16).	Consensus

Best practice note—7

Ageing with an amputation

The key common issues relevant to someone ageing with an amputation that can be prevented or diminished, or for which compensatory strategies can be used, are:

- arthritis
- psychosocial and mental health
- balance and risk of falls
- skin care
- weight control
- cardiovascular disease and fitness
- memory and cognition.

For most people as they age, maintaining their health, lifestyle and independence is important to them and their family. The person, carer and multidisciplinary team should focus on supporting the person to perform actions and adopt routines, and providing equipment, supports or services, that maintain, diminish or prevent factors that can be influenced (e.g. weight control and prevention of diabetes, fall minimisation, stump hygiene to prevent complications).

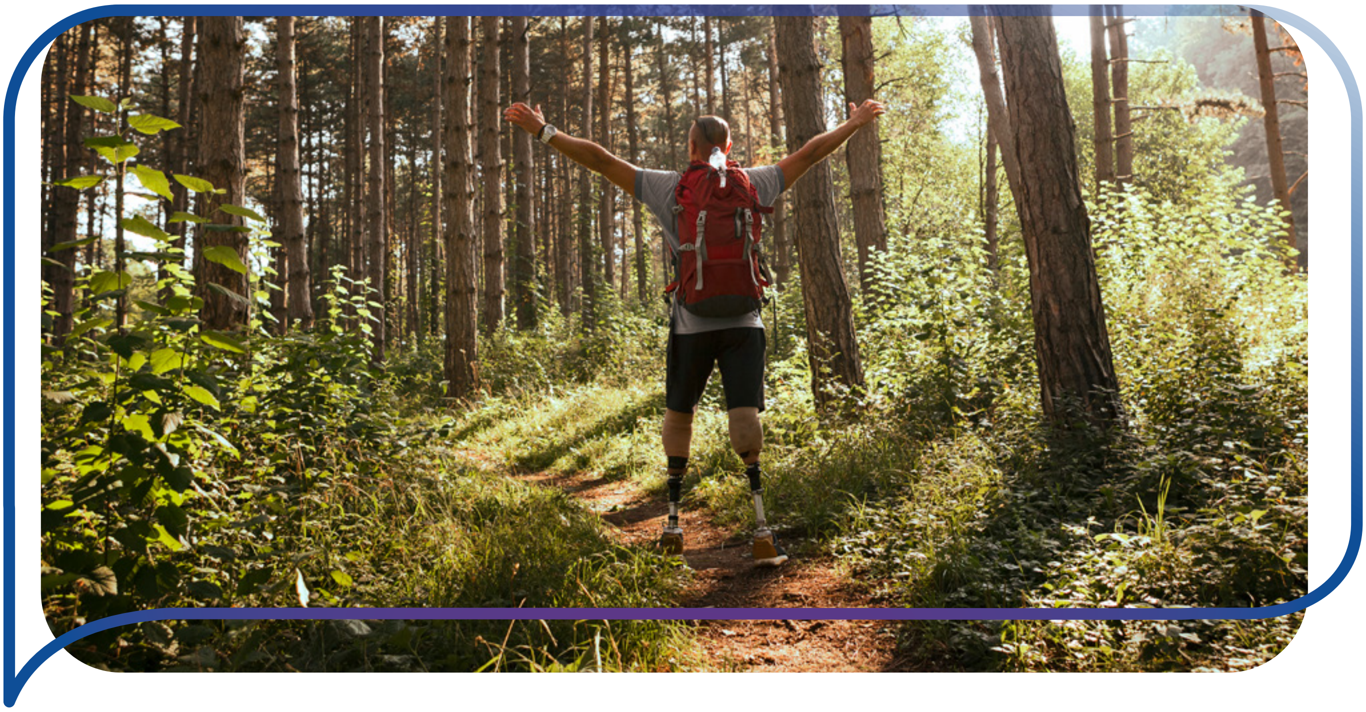
Resources—9

Information for people with a limb amputation

Ageing with an amputation

Information and resources for the person and their family

- *Coping with aging and amputation (How changing the way you think could change your health)*
  See: www.amputee-coalition.org/resources/coping_with_aging_and_amputation
  (Amputee Coalition -USA)
- *Aging gracefully with an amputation*
  See: https://opedge.com/aging-gracefully-with-an-amputation/ (article from The O&P Edge)



8.13 Body weight and fitness

Maintaining a healthy body weight and fitness is important for any person, to enhance life in general, long-term functioning and outcomes. Maintaining a healthy body weight and fitness are critical for people with an amputation, particularly for those with lower limb amputation. A combination of exercises for people with lower limb amputation have been shown to have positive effects on cardiovascular fitness, muscular fitness and functioning (distance walked, functional mobility and capacity) [90]. Yet many people with limb amputation (whether related to trauma or to vascular conditions) are vulnerable to not exercising adequately, and can experience weight gain and reduced cardiovascular fitness [91].

Some contextual factors that may contribute to weight gain and lower fitness are:

- the time spent in hospital
- psychosocial concerns and adjustment to the amputation (including body image)
- being sedentary and experiencing long periods when mobility is restricted due to medication and pain management issues (refer to Section 9.4 Pain)
- stump (residual limb) changes (see Section 8.14)
- delays in treatment, prosthetic trial and supply
- particular stages in the support pathway such as when therapy stops.

The research literature on body weight gain has focused primarily on male participants with lower limb amputations. The research shows that males with a lower limb amputation can experience a 8–9% weight increase, and in some studies up to a 14 kg increase, after the amputation [92, 93]. One study identified that, for some participants, body mass index (BMI) at six weeks post amputation was lower than their pre-amputation BMI, but by 12 months after amputation, their BMI was higher than before the amputation and their overall mobility decreased [94]. The research also shows that the weight gain for people with lower limb amputations can be slow, but for 40–42% of people with a lower limb amputation, their weight starts to increase at 12 weeks after amputation and continues for years [95, 96]. This is consistent with the preliminary research for this guidance. A comprehensive file review of a sample of 20 participants at icare revealed that 40% of participants had a weight increase (all of whom had lower limb amputations) and only 10% had a weight decrease. The weight increase contributed to difficulties with fitting the prosthesis, delays in provision of the definitive prosthesis, or complications which led to requiring a new socket.

The research affirms that physical rehabilitation treatments and therapy do not increase cardiovascular health or fitness [97, 98]. Physical rehabilitation treatment is designed to focus on other body functions (structural, muscular and movement functions) and prosthetic use, rather than increasing levels of fitness. Assuming that a high K level (greater potential ability to walk with a prosthesis) reflects a higher level of cardiovascular fitness is also not appropriate. K levels (Medicare Functional Classification Levels—MFCL) are a means to indicate the potential benefit of a prosthesis after a lower limb amputation. A systematic review did not find any connection between K levels and cardiorespiratory fitness [99, 100].

Research shows that dietary intake is related to cardiovascular health and fitness. A study of people with lower limb amputations (in the United Kingdom) revealed they had a higher fat, sugar and salt intake in their diet, combined with being overweight and obese, compared to people without an amputation. Dietary intake and weight are indicators of cardiovascular disease risk in people with lower limb amputations [101].

Only a few studies have included female participants. The degree to which an increase in weight, decrease in cardiovascular fitness or impacts of hormonal changes (e.g. menopause) may affect females with an amputation is not known. Women with lived experience also highlight the need to proactively manage weight and seek advice from peers and health professionals (including their prosthetist) during pregnancy.

The research, and expert and experiential knowledge of the working party confirms there are two reasons why men and women with lower limb amputation need to avoid weight gain and maintain their fitness after an amputation. These are:

- fitness for walking and mobility to maintain prosthetic fit; increased mass in the stump may result in skin trauma, associated wounds and discomfort
- ‘fitness for life’ to maintain overall health and general wellbeing.

A variety of clinically based assessment and measurement methods and tools are used by health professionals to assess and measure fitness. The guidance is not a clinical guideline for a specific health professional discipline. The information and resources for weight and fitness monitoring included in the guidance are for generic, easy-to-use and accessible tools that any person can use.

	Recommendations	Grade
19	Before discharge from inpatient rehabilitation or hospital (as early as possible), the multidisciplinary team (including dietitian as required, case manager and GP,) and the person should discuss and develop goals and a strategy for weight management. Resources box 8 describes a useful approach (the 5A’s approach to weight management).	B^{Q}
20	The person should establish an ongoing exercise routine and healthy lifestyle habits to maintain cardiovascular fitness and weight management, with the assistance of their multidisciplinary team (including case manager and GP).	A
21	The person’s exercise routine and healthy lifestyle habits should be included in goal planning and reviewed at regular intervals along the support pathway by the multidisciplinary team. A team member should take responsibility for monitoring the person’s steps and activities to achieve the goal, their weight and motivation.	Consensus

Best practice note—8

Body weight and fitness

Interventions and support for the person to maintain weight and fitness should commence as early as possible. The person needs to maintain weight and fitness for its benefits to their post-amputation walking and life.

Barriers to changing behaviour and diet [102]:

- habit
- too little money
- stress or depression
- underlying conditions
- low informal support.

Facilitators and options for managing weight and fitness well [22, 42, 90, 103, 104]:

- focusing on participation activities (exercising incidentally with activities of daily living) rather than on mobility or potential for ambulation
- structured approaches, e.g. setting goals and motivational interviewing
- tailoring exercise, diet, education and emotional support to the person and their context, including referral to appropriate health professionals (e.g. dietitian)
- telephone-based or internet-based support over a number of weeks (e.g. with a health coach or a digital app)
- use of measurement aids such as weighing scales, pedometers
- peer support.

Best practice note—9

Body weight and lower limb amputation

If the person with a lower limb amputation is overweight or obese, even small amounts of weight loss will help to improve their mobility using a prosthesis, and improve their general health and wellbeing.

Resources—10

Information for healthcare professionals

Body weight management

(Adapted from the NHMRC *Clinical practice guidelines for the management of overweight and obesity in adults, adolescents and children in Australia* [105])

The 5A's approach to weight management—after amputation

Ask and Assess—current lifestyle behaviours and body mass index, co-morbidities and other factors related to health risk

Advise—promote the benefits of a healthy lifestyle, and explain the benefits of weight management after amputation and its impact on mobility

Assist—develop a weight management program that includes lifestyle interventions tailored to the person with an amputation (e.g. based on severity of obesity, risk factors, co-morbidities), and plan for review and monitoring

Arrange—regular follow-up visits, referral as required (e.g. to a dietitian, exercise physiologist or psychologist) and support for long-term weight management

Best practice note—10

Assessment of cardiovascular risk factors

For the assessment of risk for cardiovascular disease and diabetes use a combination of two risk factors: body mass index (BMI) (which should be adapted for people with a limb amputation) and waist circumference. BMI is not the only way to measure cardiovascular risk.

Resources—11

Information for healthcare professionals

Assessment of cardiovascular risk

Body mass index (BMI)

An online resource for measuring BMI after limb amputation is available through the **Amputee Coalition** (USA). The calculator uses an adapted formula (weight without prosthetic device, percentage of total body weight of missing limb and estimated body weight). The BMI categories (under, normal, overweight and obese) are adjusted accordingly. The calculator is not validated but does give a reasonable estimate.

For an explanation of BMI, see:
www.amputee-coalition.org/limb-loss-resource-center/resources-filtered/resources-by-topic/healthy-living/about-bmi

For the calculator and instructions, see:
www.amputee-coalition.org/limb-loss-resource-center/resources-filtered/resources-by-topic/healthy-living

There are some exceptions to be aware of when using BMI to assess healthy weight. Under, normal, overweight and obese categories for BMI vary for people of Asian background (lower), and for people of Polynesian background, elite athletes and older persons (higher).
See: www.health.gov.au/topics/overweight-and-obesity/bmi-and-waist

8.14 *Managing stump (residual limb) complications*

There is continuing discussion on the most appropriate term for the residual limb. Health professionals often use the phrase 'residual limb', although others think that this term refers to a remaining and intact limb. Following the advice from people with lived experience involved with the guidance development and in the interests of person-centredness, we use the word stump.

All people experiencing a limb amputation have changes to the stump over time and care of the stump is a continuous process [106]. Stump changes are more pronounced in the first one to three years after amputation, particularly changes in the stump shape and volume; changes also depend on the site of amputation, and whether it is an upper or lower limb amputation. There are also likely to be stump changes from day to day (e.g. in hot versus cold weather, or related to activity level). These changes may occur throughout the person's life.

Also women with a limb amputation may experience changes to the stump during their pregnancy e.g. swelling [107]. Each person needs to seek support and advice from the multidisciplinary team and their peers on how to manage these changes.

Often there are other more significant concerns and potential issues with the stump that mean the person needs support and advice. These include [108-111]:

- trauma from falls
- changes to the shape and volume of the stump
- complications with wound healing
- phantom limb pain (refer to Section 9.4 Pain)
- flap necrosis or infection (refer to Section 9.5 Infections)
- spur formation
- skin breakdown
- development of neuroma
- contact dermatitis
- phantom sensation.

Some of these issues require the person to be re-admitted to hospital for treatment.

Best practice note—11

Stump complications

It is important that the person, their family, the multidisciplinary team (including the GP) and the funder recognise the impacts of potential stump issues. These issues can impact the person's progress on the pathway at any phase. For example, delay in fitting the prosthesis heightens the need for trialling componentry and could result in a change in support needs, or further treatment and rehabilitation. Accordingly, there may be requests to the funder for changes to, or additional, treatment and equipment (e.g. a change to the socket).

8.15 Usability and practicality of the prosthesis

Prosthesis prescription is crucial to the person's outcomes. Fit and comfort are important, but usability and practicality are also important. Contextual factors influence the person's use of the prosthesis. Trialling a prosthesis, componentry or walking aids in a clinic will not provide the opportunity to check whether the prosthesis components are fit for purpose in real-life circumstances. Trials also need to occur at home and in the community. It is not only the movement, action or activity that needs to be tested, but also the factors in a person's environment and real life that may impact their use of the prosthesis. These factors include the natural or built environment, noise, time pressures, weather conditions and light, but also whether people are watching them, and the meaningfulness of the activity for the person. For example, walking around with a lower limb prosthesis in a clinic is different to walking on carpet, a wooden verandah, grass or road surface and with a bag of shopping. Likewise, for a person with an upper limb prosthetic, picking up an item in a clinic is different to picking up a special breakable item at home or giving someone a gift. Personal factors and situations can also impact on the person's use of the prosthesis, for example, fatigue, whether the person underwent multiple amputations (upper and lower, or bilateral) or whether the dominant arm was involved (amputation or brachial plexus injury).

It is critical that the prosthesis and componentry is the best and most appropriate option for the person, determined after all relevant factors are considered, and that componentry is trialled for a suitable time. Any trials should be in collaboration with other members of the multidisciplinary team (e.g. occupational therapist) and over a reasonable period of time (e.g. two weeks). Trial and use of the prosthesis in different contexts will assist the person's confidence in its use and practicality, and their commitment and sense of ownership.

Best practice note—12

Trial of prosthesis componentry

Best practice prosthetic prescription is when trial of componentry is standard practice. The trial should occur:

- over a number of weeks
- in the real world
- in collaboration with the multidisciplinary team.
- The trial and practice should include time:
- in the home, including undertaking activities of daily living, e.g. self-care and domestic tasks
- performing activities relevant to the person's goals
- at work (if applicable)
- performing relevant leisure activities.

It is appropriate to include a trial of the prosthetic device, a report on the outcome and a quote for the final prosthesis in the quote submitted to the funder.

8.16 Prosthesis maintenance

Ensuring the prosthesis is adequately maintained and repaired is critical to optimising the person's use of the prosthesis and therefore their functioning in terms of activities and participation in life roles. Ownership and responsibilities for maintenance can be confusing for the person and their family. Some aspects are explained below.

1. The prosthesis is owned by the person using the prosthesis, even though it is paid for by the funder (e.g. Lifetime Care and Support or Workers Insurance).
2. The person needs to ensure they understand the maintenance requirements for their prosthesis and who is responsible. They should discuss this with the prosthetist and refer to the information sheet *Limb prosthesis maintenance—general information for users and their family* in Section 13 Resources.
3. The prosthetist and prosthetic service provider are responsible for providing the maintenance information and to use a maintenance and reminder system. The system should prompt the person with the prosthetic limb to schedule maintenance checks with the prosthetist. This should be done in a person-centred way so that the person (and, where appropriate, their family) is empowered to be independent in managing their prosthesis maintenance, and in planning prosthesis review appointments and repairs.
4. The prosthetist should check the prosthesis and review the person's use of it at least once per year (refer to *Limb prosthesis maintenance—general information for users and their family* in Section 13).
5. The responsibility for doing maintenance checks and routine maintenance tasks is shared between the owner or their family, and the prosthetic service provider. Repairs of the prosthesis are the responsibility of the prosthetist, prosthetic service provider and manufacturers (refer to *Limb prosthesis maintenance—general information for users and their family* in Section 13).
6. In the icare schemes, the funder pays for the warranty on componentry and usually for the repairs of the prosthesis (due to normal use over time). The details of what is approved are in the funding approval provided to the prosthetist and the person (refer to Section 8.17 Communication and Section 13 Resources).
7. Communication forms provide mechanisms to seek and gain information to be shared by all parties (the person, the prosthetist, the prosthetic service provider and the funder). The funder can request details of warranty and costs from the prosthetist on the Prosthetic Request Form. Information is also repeated in subsequent forms (cost approvals) (refer to Section 8.17 Communication and Section 13 Resources).

8.17 Communication

Decisions and timing of services

All health professionals, prosthetic service providers and funders of services need to be aware of the positive impact of timely and good communication on the person's progress along the support pathway. Good communication involves minimising delays in decision-making and the timing of services. The research has shown, for example, that waiting for an unnecessarily long period of time for a prosthesis can negatively impact both physical and psychosocial aspects of recovery and quality of life [89, 112]. Delays have been known to occur in any phase of the support pathway. Delays can be minimised by:

- providing adequate information on assessment results and the reasoning behind requests
- providing adequate explanation of requests or pathways when these are unexpected, for example, the reasons why the person abandoned the prosthetic and requires another (i.e. what happened in the trials of the prosthetic, what has changed to precipitate another prosthetic). If the detail is not present, the funder needs to request further information from the provider (e.g. prosthetist, equipment supplier, therapist), which causes delays in decision-making about funding.
- having adequate systems in place with the funder to avoid delays in decision-making and communication on funding requests
- equipment suppliers having appropriate systems to ensure prompt delivery of products
- service providers having appropriate systems to minimise waiting lists.

Communication between stakeholders

To support good communication and practice, some documentation was revised during development of this guidance, in collaboration with service providers and funders. The documents relate to requests to funders, approvals, and reviews of services and products. The documents were designed for use within icare, but can be adapted for use in other systems if appropriate.

The documents relate to communication between funders, the multidisciplinary team (including the GP and case manager), and the person needing a prosthetic limb and their family. The documents are:

- a prosthetic request form to be completed by the prosthetic service provider
- a prosthetic approval templates to be completed by the funder
- a prosthetic review record to be completed by the prosthetist

(refer to Documentation related to requests and funding in Section 13).

The revised documents include key information such as the prosthesis prescription, the person's goal and the necessary steps to achieve that goal, training requirements, assessment findings, the prosthetic and componentry options trialled, and the warranty details. To optimise communication and transparency, copies of the completed documents should be sent by the author to the person needing the service and product, the funder, the case manager and GP, and any other relevant member of the multidisciplinary team (in line with the person's written consent). The information in the documents is essential to the transparency of the process, enhances the person's health literacy and empowers self-management of their health condition.

The revised documents are only one of a range of communication strategies that stakeholders can use to enhance communication. Other communication methods include email communication, assessment and progress reports, team meetings and case conferences (including the person), either face to face or using digital technology for telehealth (refer to Section 8.19 Access to services and telehealth).

Best practice note—13

Communication

1. Action is warranted by any of the multidisciplinary team, service provider or funder to minimise unnecessary delays in the provision of equipment, services and supports along the support pathway.
2. Copies of completed documents such as prosthetic requests, prosthetic reviews and funding approvals should be sent to the person needing the prosthetic limb or their family, the case manager and the GP at a minimum, as well as any other relevant multidisciplinary team member. Forwarding copies of the Prosthetic Request Form to all parties should be the provider's routine practice.
3. The information provided in the documents is essential to the person's health literacy, and empowers and facilitates self-management of their health condition.

8.18 Access to a multidisciplinary team

The opportunity to involve multiple health professionals and have access (when necessary) to a multidisciplinary team in any phase of the support pathway is essential for meeting the support needs of the person, from the time of their injury and throughout their life.

The term multidisciplinary team is used in this guidance to refer to the team of health professionals and peer support workers who provide rehabilitation treatment, guidance and support to the person (and their family) before and after an amputation and throughout the person's life. The health professionals that may be involved include a case manager, dietitian, exercise physiologist, general practitioner, medical specialist (e.g. orthopaedic surgeon, neurosurgeon, pain specialist), nurse, occupational therapist, physiotherapist, podiatrist, prosthetist, psychologist, rehabilitation specialist, social worker, and workplace or vocational rehabilitation provider.

A range of people from the multidisciplinary team may be involved along the support pathway, depending on the person's circumstances, progress and needs. The timing and frequency of contact and who is involved may vary. It is critical that the person is aware and acknowledges that no one health professional has the knowledge, training or expertise to meet all of their service, information and support needs. The multidisciplinary team need to reinforce this with the person when necessary.

	Recommendations	Grade
22	At any stage after amputation, the person should be referred for a review by the relevant multidisciplinary team member(s) when concerns or issues arise. The referral can be initiated by the person or anyone from the multidisciplinary team involved in the person's care and support. The case manager is likely to be the first point of contact if already involved.	Consensus

8.19 Access to services and telehealth

A person with an amputation or their carer may face barriers to accessing the specialist services and supports they need if they live in regional, rural and remote areas. These barriers include great distances from home to the service, limited transport options, accessibility of transport options, costs for travel and time taken for travel. Service contextual issues, such as availability and choice of health professionals with the appropriate knowledge, training and skills, may also be a barrier. Even if the health professional is available, there may be waiting lists. Barriers to accessing services can also exist for people in urban areas, as highlighted by the COVID-19 pandemic. Early discharge from inpatient rehabilitation may also impact access to services.

Some services, such as definitive prosthetic prescription and gait training, can only be provided face to face. However, health professionals and organisations need to consider adapting their practice to use digital technologies for telehealth or telerehabilitation so they can provide services remotely when necessary, or when a face-to-face contact is not necessary. Telehealth is defined as the use of telecommunication techniques for the purpose of providing telemedicine or telerehabilitation, medical and treatment-related education, and health education [113]. Guidance and motivational support can be added to this definition. However, telehealth is not simply talking to the person on the telephone. It needs thought, planning and design, with adaptation for each person [114, 115].

There is substantial evidence of the effectiveness of and satisfaction with telehealth generally for people with a range of health conditions. Both health professionals and people receiving telehealth services express satisfaction with this approach, especially when video is used rather than voice only. Specifically, for people with a limb amputation, research has shown:

- Telehealth is effective when used for psychosocial support and treatment of mental health conditions for people with an acquired disability (including those with limb amputation) [116-118].
- Telehealth is effective when used for physical treatments such as physiotherapy, occupational therapy and home exercise programs, for follow-ups and changing exercise-related behaviours [119-121], although it is less effective with monitoring technologies related to prosthetic rehabilitation [122].
- Telehealth for some therapies (e.g. mirror therapy for treatment of pain) has challenges but may be considered [123].
- Telehealth is effective for the prevention of infections and diabetic ulcerations [124].
- Case conferences (including the person) are often done remotely [118].

Depending on the purpose of treatment and the person's goals, and when appropriate, there may also be a need to involve or train home-based support workers or carers to provide assistance in the person's treatment and therapy. Face-to-face sessions can be used to establish a home program that involves follow-up and review via telerehabilitation.

Best practice note—14

Telehealth and telerehabilitation

- Telehealth and telerehabilitation should be considered as an option when face-to-face contact is not essential.
- Guidance and support should be provided to help the person set up the technology needed to receive telehealth or telerehabilitation services.
- The funder may consider providing assistance to fund aspects of the technology set-up and building the person's skills for using the technology, particularly if it is more cost-effective than face-to-face services (e.g. if travel costs are prohibitive), if there are physical or geographical barriers to accessing services, or if the person does not have the resources to do it themselves.
- Consider whether telehealth or telerehabilitation options are limited by the technology available (e.g. audio compared to video technology).
- Telehealth or telerehabilitation should be trialled and feedback sought from the person before proceeding any further with these services.
- It is the responsibility of the health professional to develop the necessary skills, knowledge and expertise to conduct telehealth and telerehabilitation.

Resources—12 Information for healthcare professionals

Telehealth and telerehabilitation

Professional associations have developed guidelines and resources on telehealth and telerehabilitation for health professionals. Some were developed in response to the COVID-19 pandemic but are relevant for treating people with any health condition.

- Resources are available for:
- allied health professionals—see: ahpa.com.au/resources (Allied Health Professions Australia)
- general practitioners—see: www.racgp.org.au/running-a-practice/technology/clinical-technology/telehealth (Royal Australian College of General Practitioners)
- occupational therapists—see: www.otaus.com.au/member-resources/covid-19/telehealth (Occupational Therapy Australia)
- prosthetists—see: www.aopa.org.au/documents/item/862 (The Australian Orthotic Prosthetic Association)
- physiotherapists—(Australian PhysiotherapyAssociation)
- psychologists
- rehabilitation physicians—see: www.racp.edu.au/fellows/resources/digital-health (The Royal Australasian College of Physicians)

9. Connected health issues

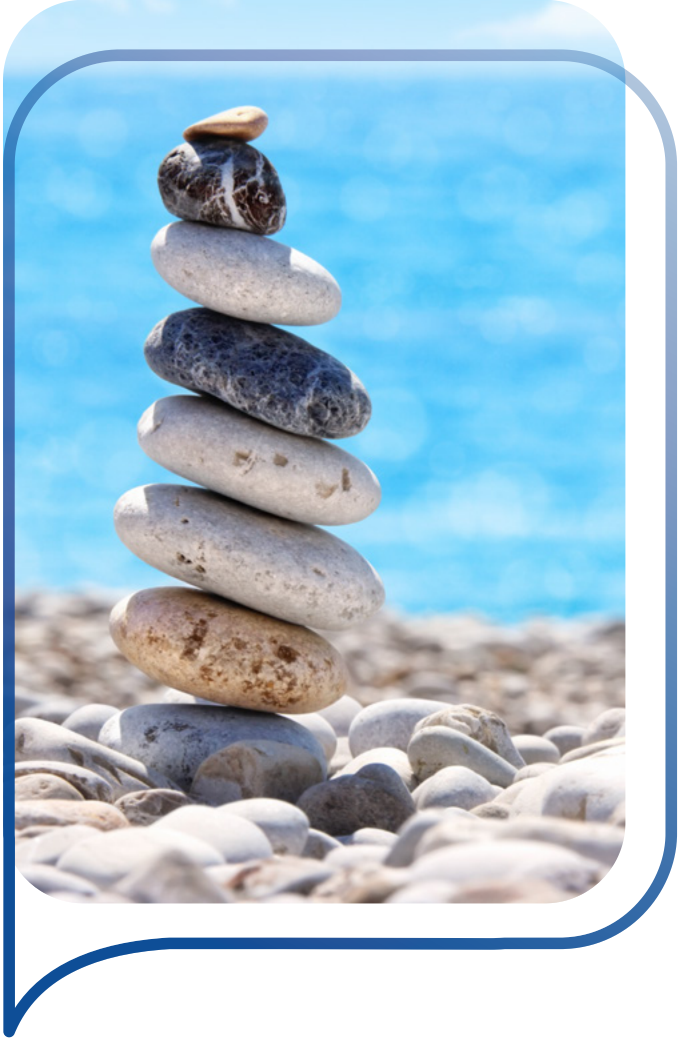
Some health issues are commonly connected with having an amputation. Because these health issues are so common among people with an amputation, the person should be carefully monitored for these health issues throughout all phases of the support pathway. Sometimes these are called secondary conditions (refer to the Glossary). We do not include all the possible health issues below, but describe the common issues identified (from research and experiential knowledge) during development of the guidance.

9.1 Psychosocial wellbeing and mental health conditions

Psychosocial wellbeing, quality of life, body image and sexuality are connected. Psychosocial adjustment after a limb amputation is complex, with interplay between individual psychological and environmental factors [125, 126]. Frequently, people experience anxiety and depression before and after the amputation [127, 128]. Traumatic injury-related amputation is a risk factor for the person also experiencing post-traumatic stress disorder [129]. Post-traumatic stress is also associated with more mental health disorders of anxiety and depression, and poorer outcomes with activities and participation [130]. The presence of phantom limb pain after amputation is also a risk factor for depression, poor psychosocial adjustment and withdrawal from social activities [130]. The research is clear that early assessment and psychological treatment, before and after surgery (because of the association with adjustment) and also for some months after the amputation (some suggest up to 12 months after), facilitate the person's psychosocial adjustment [126].

The person's response to limb amputation will be influenced by a range of personal and contextual factors [126]. Psychosocial adjustment varies between people. Some people perceive the limb amputation as devastating, and others perceive the major life-changing event as a challenge and find a new meaning and purpose in life. There are three overlapping patterns related to the coping styles that people use in their psychosocial adjustment [130]:

1. active/confrontative (direct planning, taking action, problem solving) versus passive/avoidant (dependence on others, avoiding adjustment issues)
2. optimistic/positivistic versus pessimistic/fatalistic (challenge for personal growth versus surrender to a sick role)
3. social/emotional (seeking social support, seeking audience for venting, asking for help) versus cognitive (internal self-examination, working on acceptance, denial).



Strategies people use to cope and adjust to an amputation can influence their outcomes. If the person actively problem solves, tends to be optimistic and proactively seeks support, their psychosocial adjustment will be positive. If the person avoids treatment and rehabilitation, and is not engaged in their own self-management, more severe emotional distress and poor psychosocial adjustment is likely [130]. Adjustment may be relatively immediate but, for many people, the emotional adjustment can be delayed. They may then experience possible triggers later when confronted with changed circumstances, such as prosthetic fitting, resuming activities and participation, or other personal or environmental factors [130, 131]. Some people think they will get better on their own, and do not need psychosocial support services [132]. However, they may still be at risk of experiencing depression many years later [133]. One large study noted that people with an amputation after a traumatic injury were more satisfied with their activities and participation than people with dysvascular amputations [134]. Better mental health and satisfaction has also been shown to be higher for people with limb amputation who return to work after the amputation [132, 135].

Counselling and psychological support should be offered and made available to the person and their family before (where possible) and again after the amputation, throughout the care pathway when needed, and at key life events such as the first anniversary of the amputation [24, 136]. Psychological treatment via telehealth is a realistic and established option when there are barriers to face-to-face treatment.

	Recommendations	Grade
23	If a psychologist is not currently involved, the person should be regularly screened for psychosocial issues by the treating health professionals using a validated tool (PHQ-2 and GAD-2; refer to Resources box 8)	A
24	The person should be referred by the treating doctor (monitored by the case manager) to be assessed for psychosocial concerns before the amputation.	B^Q
25	Within the first three months after the amputation, the person should be assessed to determine their need for psychosocial support (e.g. in terms of adjustment, need for peer support, treatment for anxiety and depression, medication review).	B^Q
26	The case manager should encourage the person to maintain contact with their GP for monitoring and referral for appropriate supports (e.g. psychosocial) as required. (Refer to recommendation 16)	Consensus
27	All multidisciplinary team members and the funding body are responsible for monitoring the person throughout the support pathway, and advising the case manager and GP if there are concerns. (Refer to Section 8.9 regular screening and Section 8.11 Lifelong monitoring)	Consensus

9.2 *Body image*

Body image is complex and multidimensional. Body image is a conscious, ‘top-down’ cognitive perception of your own body. It involves the interaction of physical body appearance, and perceptual, cognitive and behavioural aspects of body experience [137]. It is also influenced by factors such as other connected health issues, co-occurring health conditions, and personal factors like age, gender, education and health literacy.

Challenges around body image are a common issue following limb amputation, particularly for people with upper limb amputations, and particularly at approximately 10 years after the amputation [137-139]. The person’s body image may not be as affected before this time, and then it recovers again sometime after 10 years [140]. The reasons for this are not clear, although the research confirms the need for lifelong monitoring of psychosocial wellbeing and mental health. People with phantom limb pain are more likely to experience body image concerns, which is supported by research on dreams and body image [138, 141].

Self-esteem seems to be independent of body image, and not affected for people with a lower limb amputation, unless there is phantom limb pain [137, 142]. There appears to be no difference in body image challenges and concerns between men and women, nor by the level of the amputation. Although women who report experiencing body image disturbance also report feeling more depressed. [130]. People with two or more limb amputations have more body image anxiety and dissatisfaction [140].

Perception of how they look seems to be a key factor in the level of body image anxiety and social discomfort the person may experience [139]. How the person perceives their appearance and body image also facilitates their active involvement in prosthetic fitting and rehabilitation [130].

Body image is also associated with how well the person has adjusted to their changed circumstances and attempted to integrate the prosthesis ‘into’ their body image [143]. In our research for the guidance, people with lived experience (experiential knowledge) confirmed this key message, with one person commenting they had “an emotional connection with my prosthesis”.

Another influence on body image is the level of physical activity the person undertakes. This is often an underestimated link for people with a limb amputation. People with amputations have reported being involved in sport because of the health benefits, social interaction and stress relief, but also because it supports their psychosocial wellbeing in terms of improving self-esteem and body image [91].

Best practice note—15

Body image

Body image is complex and multidimensional but will likely be affected following a limb amputation.

Concerns and anxiety around body image can occur in the longer term. The multidisciplinary team should not assume the person will not have body image challenges after the amputation; challenges may occur years later. The person should be referred for psychological assessment (and possibly peer support) services as appropriate.

Facilitators to minimise body image concerns include:

- working towards ‘integrating’ the prosthesis as a part of their body
- active engagement in their prosthetic fitting and rehabilitation
- the best possible cosmetic appearance of the prosthesis
- participating in exercise and sport (own exercise routine, or social or competitive sports).
- Factors that are likely to negatively influence body image and self-esteem include:
- the presence of phantom limb pain
- amputation of two or more limbs.

9.3 *Sexuality and sexual health*

Sexuality refers to the way people experience and express themselves sexually. Sexual health (or sexual wellbeing) is the state of physical, emotional, mental and social wellbeing in relation to sexuality. Literature that reports on sexuality and the impacts of amputation on sexual health of adults is limited, and the majority of studies concern only males [144-146]. While sexual interest remains at normal levels after limb amputation, there is a connection between psychosocial functioning, body image and sexual functioning for a person of any gender experiencing limb amputation [144, 146-149]. There are reports that nearly 75% of adults with limb amputation experience some restriction in sexual activity following the amputation. In men with lower limb amputation, the factors contributing to sexual dysfunction are the person's emotional state, pain, level of amputation and quality of life. The impacts are greater for males with transfemoral amputations than for males with transtibial amputations [144, 150]. For women with lower limb amputation, peer support was helpful in dealing with the challenges of dating and intimate relationships [151].

People with lived experience of limb amputation report that health and rehabilitation professionals infrequently discuss sexuality with the person with limb amputation [144, 145, 152]. Among people with limb amputation who report some restriction in sexual activity, fewer than 10% have received guidance or counselling from their health professionals on how to manage the issues [130]. Silence on sexuality from the person does not imply the person has no concerns. It is important that sexuality is considered in standard rehabilitation care [144].

A gradual stepwise approach called Permission (P), Limited Information (LI), Specific Suggestions (SS), Intensive Therapy (IT) (commonly referred to as the PLISSIT approach) is used by health professionals for people with sexuality concerns [153]. The approach has been used with people who have acquired disability or chronic illness [154].

The PLISSIT approach uses the premise that most people experiencing sexual problems can resolve them if they are given permission to be sexual, to desire sexual activity and to discuss sexuality; if they receive limited information about sexual matters; and if they are given specific suggestions about ways to address sexual problems. Greater knowledge, training and skills are required of the practitioner as the level of intervention increases.

So a 'generalist' health professional may consider they have the competency (knowledge and expertise) to support the person using the levels permission, limited information or specific suggestions (PLISS) levels, but not necessarily for the subsequent level(s) [153, 154]. The key factor is seeking the person's permission (to be sexual and discuss sexuality), reflection and review at each step. Permission helps to normalise discussion of sexuality. Some people may seek to skip the first level (s) and wish to go straight to intensive therapy [155].

Best practice note—16

Sexuality

- Sexuality is frequently a concern for people with a limb amputation.
- Members of the multidisciplinary health and rehabilitation team should ensure that there are opportunities for sexuality to be discussed with the person.
- Review medication to exclude whether it is having an impact on sexual health.
- The PLISSIT—Permission, Limited Information, Specific Suggestions, Intensive Therapy—approach is a useful framework for health professionals to use with people who have had an amputation.

Resources—13

Information for healthcare professionals

Sexuality

For the health professional

The PLISSIT approach
See: link.springer.com/article/10.1007/s11195-007-9044-x

Resources—14

Information for people with a limb amputation

Information and discussion from peer websites

- *Dealing with sex and intimacy after an amputation*
  See: amputeestore.com/blogs/amputee-life/dealing-with-sex-and-intimacy-after-an-amputation (Amputee Store)
- *Sex and intimacy after amputation*
  See: livingwithamplitude.com/article/sex-and-intimacy-after-amputation (Amplitude)

9.4 Pain

People who have sustained a traumatic injury and undergone a limb amputation can potentially experience different types of pain. Pain is possibly the most significant and frequent factor affecting people with an amputation [156, 157]. There seems to be no difference in the occurrence of amputation-specific pain between males and females [158]. If all types of pain are taken into account, including musculoskeletal pain (e.g. back pain), between 72% and 83% of people with traumatic injury-related amputation report pain that is problematic and interfering with their lifestyle and functioning [159-162]. Sometimes the cause of the pain can be identified. Pain is most often due to neuromas, but can also be caused by inflammation and oedema, soft tissue calcifications, bony spurs, soft tissue infection, overuse injuries, bursae and skin lesions [163]. However, phantom limb pain and neuropathic pain (rather than musculoskeletal pain) is the most common type of pain reported by people with amputations. More than half of people with an amputation report phantom limb pain, although those with an upper limb amputation are more likely to experience phantom limb pain than people with lower limb amputations [162, 164, 165].

The types of pain and their features are described below [166]. Stump pain refers to the pain in the limb remnant that occurs either as the result of the surgery, swelling associated with the surgery, a fall that results in a bruise, or an infection.

Phantom limb pain

Type/name	Description
Phantom limb pain	The experience of painful sensations in the area of a missing limb. The pain features vary.
Phantom sensation	A feeling that the amputated limb still exists. The person may experience sensation such as itchiness, coldness or twisting of their limbs or digits, movement of their limb, or telescoping in the part of their body that is not there anymore. Telescoping is the sensation that the amputated limb has become smaller than it was before the amputation.
Neuropathic pain	Burning, electric shock-like, pricking, pins and needles, sharp, shooting, hot-burning, tingling, squeezing, cold, electric or shooting pain.

Why or how phantom limb pain happens is not clear. The most common theory is that part of the brain (the motor cortex) reorganises the body's somatosensory maps (a representation of the limb with sensations such as pressure, pain or warmth). There is a tension between the persistence of the previous map (cortical organisation), and the 'new' map and input from the system of nerves that branch out from the brain and spinal cord (peripheral nervous system) [167-169]. The features of phantom limb pain vary between people and can include neuropathic pain [170]. Phantom limb pain can begin immediately after the amputation (in 75% of people) or weeks later [171]. The pain can be short-lived or lifelong, continuing for 50 years or more [172, 173]. In one study there was a potential for phantom limb pain for people with an amputation because of vascular disease and another study there was also potential with people prescribed an osseointegration prosthesis [174, 175].

The risk factors and triggers for phantom limb pain identified in the research include:

- presence of post-traumatic stress disorder and/or depression, and catastrophising [142, 165]
- stress and poor adjustment to the amputation [138]
- presence of pain before the amputation—this has an impact on the occurrence of pain immediately after surgery, but does not necessarily influence whether the pain persists [167]
- triggering by visceral stimulation (e.g. bowel or bladder filling or emptying), although this improves over time after the amputation [176].

Various approaches, such as intensely focused ultrasound, have been trialled to identify the pain generators [177]; however, none of the results are definitive.

There is a significant body of research on the treatment of phantom limb pain. However, there is no substantive evidence on the effectiveness of most of these treatments. Thus, it is difficult (for all but a few) to say whether a treatment will definitely assist to reduce the pain or not.

Treatments that may influence phantom limb pain are:

1. Mirror therapy: The premise of mirror therapy is to focus on the sensorimotor cortex in the brain and provide visual, sometimes tactile, input to change the perception of the phantom limb pain; however, the exact mechanism is not fully understood [171, 178]. This approach involves the person visualising the limb moving in a natural manner using a mirror. It might also involve tactile input, such as stroking the phantom or stump with different textures, and a graded motor imagery approach using objects [179]. While a review four years ago considered there was insufficient evidence to suggest that mirror therapy could influence the level of phantom limb pain [180], research since that time suggests benefits of mirror therapy over a number of weeks [167, 181, 182]. Mirror therapy before undergoing amputation may also assist [183]. A structured clinical framework for mirror therapy has been developed and validated [179].
2. Psychological treatment: The presence of anxiety before the amputation may contribute to phantom limb and stump pain after the operation. This suggests treatment for anxiety before the operation may influence post-operative pain positively [184].
3. Medications: Some drugs have been shown to be helpful, although opioids should be avoided or their use minimised where possible because of side effects and addiction issues [167, 185].
4. Injections: Nerve root ozone injections combined with injections to the stump have been trialled recently, but more research is required to establish whether it is successful [186]. There has been some success with nerve blocks [187].
5. Surgery: Surgery involving targeted muscle reinnervation (TMR) rather than a traditional neurectomy has been beneficial in reducing pain for people with either upper or lower limb amputations. Preventing or treating neuromas with TMR also provided pain relief in most cases [188-191].
6. Nerve stimulation: Nerve stimulation of selected areas of the spinal cord has been trialled and remains in an experimental phase. The results were primarily unsuccessful for phantom limb pain, although the researchers suggest that using radio frequency and different implant strategies may be more accurate, and produce better results [192-195].
7. Transcutaneous electrical nerve stimulation (TENS): TENS has not been rigorously assessed for its effectiveness in the management of phantom limb pain nor stump pain at this time [161].
8. Acupuncture: Acupuncture has also not had adequate research to demonstrate its effectiveness in managing phantom limb pain [196].
9. Muscle relaxation: Muscle relaxation combined with mental imagery and phantom exercises has been shown to reduce the intensity and bother of both phantom limb pain and phantom limb sensation [197].
10. Tactile desensitisation immediately after the operation: The desensitisation program used in studies was therapist guided but self-administered by the person. The treatment involves gentle massage and percussion (tapping and rubbing) every 3 hours while awake, using either a mapping approach or a random order of dermatomes. This approach, done as an inpatient or at home (with telehealth support), appears to reduce the intensity of the phantom limb pain [198, 199].
11. Eye movement desensitisation reprocessing (EMDR): EMDR is a psychological approach to change the recall and memory of the painful experience. EMDR has been used for people with post-traumatic stress disorder, so it may assist with traumatic injury related amputations. Some studies demonstrate a reduction in phantom limb pain [200, 201].

No one treatment will resolve phantom limb pain; rather the use of multiple methods is considered the best approach. Common combinations of multidisciplinary treatments include education on the mechanism of pain, mirror therapy, psychological strategies (e.g. cognitive behaviour therapy) and management strategies such as exercise and pacing. Individuals will have different preferences for and responses to treatments. The treatment plan should be developed in consultation with the multidisciplinary team, including pain experts, and the person or carer.

Musculoskeletal pain

Musculoskeletal pain is defined as an aching, sharp, dull, posture- or movement-related pain. Between 35% and 63% of people with traumatic injury-related lower limb or upper limb amputations report musculoskeletal pain, such as back pain, daily or weekly [157, 202-207].

Research shows the following influences on musculoskeletal pain:

- People with transfemoral amputations in particular report a higher incidence of lower back pain compared to those with transtibial amputations [208].
- Adaptations to gait required to walk, and for sit-to-stand and stand-to-sit tasks are associated with or cause lower back pain [203, 209-211].

	Recommendations	Grade
28	The multidisciplinary rehabilitation team is responsible for educating the person and their family on the potential for pain to occur, the need for assessment, and the value of mixed method treatment options at any phase before and after amputation.	B^Q
29	If the person experiences pain, the multidisciplinary rehabilitation team is responsible for assessment and developing a person-centred and individualised pain management plan with the person, to include different approaches (drugs, physical, psychological and mechanical treatments) and strategies for self-management.	B^Q
30	The case manager or any member of the multidisciplinary team is responsible for giving the *Tips on managing pain and limb amputation* information sheet to the person and discussing the content with them as part of the initial review with the person. (Refer to Section 13 Resources)	Consensus
31	The case manager or the members of the multidisciplinary team are responsible for providing the person with the *Tips on managing pain and limb amputation* information sheet at regular intervals, e.g. every six months post amputation or as required. (Refer to Section 13 Resources)	Consensus
32	The funding body is responsible for forwarding the *Tips on managing pain and limb amputation* information sheet to the GP and health professionals with the person's management plan.	Consensus
33	The person should provide the *Tips on managing pain and limb amputation* information sheet to their GP and discuss pain management options with their GP, including potential re-referral to their rehabilitation specialist or the multidisciplinary team at any time appropriate after the amputation. (Refer to Section 13 Resources)	Consensus

Resources—15

Information for healthcare professionals

Pain and phantom limb pain (examples only)

Australia

Australian Pain Management Association
See: www.painmanagement.org.au/

Health Engine
See: healthengine.com.au/info/phantom-limb-pain

New Zealand

Health Navigator
See: www.healthnavigator.org.nz/health-a-z/p/phantom-pain

United States

Amputee Coalition
See: www.amputee-coalition.org/limb-loss-resource-center/resources-for-pain-management/managing-phantom-pain

United Kingdom

National Health Service
See: www.nbt.nhs.uk/bristol-centre-enablement/services-at-centre/prosthetics/swelling-or-phantom-limb-sensation

9.5 Infections

This guidance refers to infection that occurs after the amputation rather than before, or as the cause of, the amputation. After surgery, even when the stump has healed, there can be changes including damage to the skin, reduced blood circulation, oedema, and changes to the nerves, muscles or bones that can lead to an increased risk of infection. When the stump is placed in the socket of a prosthesis, the area has to adapt to a humid environment, and cope with pressure and friction forces. All of these factors make the stump more prone to inflammation, infection and malignancies [212]. If there are co-occurring health conditions, such as diabetes, cardiovascular issues, burns or weight concerns, the risks are higher. The risk of re-admission for treatment of infections within 30 days after amputation is high, particularly when the person also has diabetes or vascular conditions. The potential for infection is reduced with improved surgical techniques that reduce delays with amputation [213, 214]. Soft tissue infections are generally low-grade and superficial, however, and can be treated effectively with antibiotics [215].

There is a risk of osteomyelitis (an infection in the bone) with osseointegration for a limb prosthesis, irrespective of the type of implant [216, 217]. Osteomyelitis is a more serious infection and is complex to treat, sometimes requiring further surgery [218].

Best practice note—17

Infections

For most people with an amputation, the number of infections they experience can be minimised by good hygiene and a properly fitting prosthesis [212].

The person, the multidisciplinary team and the person's carers need to:

- check the stump regularly (the person should check daily) for marks or skin breakdowns
- look out for early warning signs of infection
- treat any infection as soon as possible; do not delay or postpone treatment.

Resources—16

Information for people with a limb amputation

Infection

Information and guides for preventing infection are available from:

Amputee Coalition
See: www.amputee-coalition.org/resources/wound-care-preventing-infection

Limbs4Life (*Skin care tips for amputees*)
See: www.limbs4life.org.au/resources/skin-care-tips-for-amputees

Physiopedia
See: www.physio-pedia.com/Complications_Post_Amputation

10. Co-occurring health conditions

Sometimes the person might have another health condition that started at the time of the injury but which is not directly related to the amputation (e.g. spinal cord injury). Or the person may have another health condition before the amputation, or may develop a condition after the amputation, that is not independent of the amputation (e.g. diabetes). Similarly, the injury might involve complex orthopaedic injuries that ultimately result in multiple amputations, for example, both lower limbs, or one upper limb and one lower limb. These are referred to as co-occurring health conditions, but in the health sector, they are called co-morbid conditions (see Glossary for the definition of a co-morbid condition). In other circumstances, there is a primary health condition from the trauma and injury (e.g. burns) that is the cause of the amputation (see Glossary for the definition of a primary condition). Many amputations occur as a result of trauma and the associated complications.

These co-occurring conditions can have a significant impact on how the person progresses through the support pathway and can influence the supports needed. It is important to provide treatment, rehabilitation and support for these conditions separate to, but alongside, that for the amputation.

10.1 Burns

A severe (full thickness) burn, particularly if it is related to electricity or high-voltage power lines (e.g. workplace injury), can lead to an amputation [219-223]. The burn often complicates the recovery, treatment, rehabilitation and support the person needs. All the health professionals in the multidisciplinary team need to understand the complexity of burn injuries and healing from burns. A multidisciplinary approach is important, including input from the appropriate nursing and medical specialists.

Often a severe burn will require the person to remain in hospital for longer, with a need for more extensive treatment. The problems from burns that require specialist treatment and management include [224]:

- deep tissue damage
- infections and wound treatment
- range of motion limitations (loss of skin stretch or elasticity from skin grafts, or contractures)
- nerve damage or compromised sensation—Grafted skin is thinner and can be more sensitive, but there can also be areas of decreased sensitivity. There can be difficulties with sleeping, compression dressings for the burns, skin breakdowns, or fitting and wearing liners and the prosthesis. There can also be delayed bleeding.
- These concerns can cause complications in fitting the prosthesis or result in changes to the type of prosthesis required (e.g. an upper limb myoelectric prosthesis) [224].
- cognitive impairment—Often the person has experienced a period of unconsciousness at the time of the injury (e.g. electrocution). A large study in rehabilitation inpatients in the USA found that adults with burn injuries (particularly from electricity or high-voltage power lines) have worse memory scores on a cognitive test (Functional Independence Measure [FIM]) than people without burns [225].

Best practice note—18

Co-occurring burns and amputation

Some of the potential issues for a person with co-occurring burns and amputation include difficulties with the fitting of a prosthesis because of changed sensations, compromised skin, the friction from the prosthesis on the person's skin, infections, scarring, swelling related to the burns, and the interface with the prosthetic socket. The prosthetist, other members of the multidisciplinary team and the person should discuss, explore and trial alternative strategies to alleviate these issues.

People with co-occurring burns and amputation often need to have progressive prosthesis componentry or different types of componentry (e.g. prosthetic socket suspension). They may start with a simpler prosthesis and progress towards a more complex one as time and further healing continues.

It is also appropriate for the person to undergo a cognitive assessment (particularly their memory) when they are an inpatient.

10.2 Diabetes

People with trauma-related amputations may have developed type 1 or type 2 diabetes before (but unrelated to) the amputation, or they may develop diabetes after their amputation. Estimates on the frequency of either of these circumstances was not available from Australia or internationally. However, expert and experiential knowledge confirms that it does happen, particularly with type 2 diabetes as the weight of people can increase post amputation and as people age (refer to Section 8.13 Body weight and fitness and Section 8.12 Ageing with an amputation).

There is a significant body of research and literature on amputations as a consequence of diabetes. Australia experiences a high rate of major limb amputations every year as a result of diabetes (4.5 per 100,000 people with diabetes in 2012) [77].

Amputations may result from complications with, or a combination of, diabetic foot infections, peripheral vascular disease, osteomyelitis, neuro-ischaemia, obesity and invasive fungal infections [226-229]. People with diabetes and an amputation are at risk of infection and impaired wound healing, and have a significant risk of burns because of neurovascular changes. The literature describes high incidences of smaller area burns for people with diabetes, where there has been intentional exposure to sources of heat (e.g. soaking the limb in a hot water bath, or warming the limb close to the heater) [230]. These burns have sometimes led to amputations. People with a limb amputation who also have diabetes need to be aware of the heightened risks of burns and complications.

Although this guidance concerns trauma injury-related amputations, these potential complications and risks are particularly relevant for people with diabetes who sustain a traumatic injury and then need to undergo a limb amputation.

Best practice note—19

Co-occurring amputation and diabetes

The presence of co-occurring diabetes (commencing before or after the traumatic injury and amputation) prompts additional considerations for the range and nature of the treatment and supports the person needs at each phase in the support pathway. Complications from diabetes that health professionals and the person need to be aware of include peripheral vascular disease, risk of infection, risk of burns and slower wound recovery.

10.3 Neurological

10.3.1 Brachial plexus injury

Brachial plexus injury is complex, and typically involves significant neurological impairment, activity limitations, significant neuropathic pain (including neck pain), often phantom limb pain, participation restrictions, and orthopaedic complications such as non-union of fractures [231, 232]. There are limited but emerging technologies for treating brachial plexus injury, such as bionic reconstructions to enhance nerve signals for improved functioning [233], and therapies to treat pain (e.g. mirror therapy) [231]. A brachial plexus injury combined with a lower limb amputation can result in similar restrictions to those experienced by a person with multiple amputations of one upper and one lower limb.

A small percentage of people with a brachial plexus injury consider amputation of the limb as an option sometime after the injury. There is very limited research on the outcomes for the few people who elect to have their arm amputated. One incomplete trial of just two people who practised using a prosthesis suggested that a specific prosthesis might be useful after an amputation and a shoulder fusion [234].

Expert and experiential knowledge of members of the guidance working party suggested that the pain does not necessarily go away (as it depends on the type of pain), nor can the person use a prosthesis after the amputation (because of poor shoulder musculature). One study of nine people who elected to have an amputation after a brachial plexus injury had mixed results for the experience of pain reported one year after the amputation. Those that did experience relief had shoulder subluxation pain (related to shoulder pain and the weight of the arm), which is different to neuropathic pain. Importantly, this same study did not show an improvement in the person's functioning after amputation. It advised strict criteria for elective amputation, and in-depth discussions between the multidisciplinary team and the person, including discussion of the potential complications and limited prospects for change in function (e.g. using a prosthesis post amputation) [235].

Best practice note—20

Co-occurring brachial plexus injury and amputation

A brachial plexus injury can lead to complications and often significant pain. The research describes limited benefit and functional gains if the arm is amputated. There may be some pain reduction if pain is directly related to a subluxation at the shoulder. However, researchers state that amputation of the arm will not assist with neuropathic or phantom limb pain.

The multidisciplinary team should provide information to the person, be open to them seeking a second opinion from surgeons and allied health professionals, take time to discuss and encourage the person to make an informed decision, and be realistic in consideration of the available options and their associated risks and benefits.

10.3.2 Spinal cord injury

Although it is not common, some people will experience both spinal cord injury and a limb amputation. The support pathway for someone in this circumstance is complex. A person who has a complete spinal cord injury affecting the lower limbs but also has a lower limb amputation faces additional difficulties. It becomes even more complex for the person who has sustained paraplegia and an upper limb amputation. The loss of an upper limb has a major impact on the person's ability to transfer, and to perform daily and self-care activities.

Refer to icare's guidance on providing the support needs for adults with spinal cord injury (see: www.icare.nsw.gov.au/injured-or-ill-people/motor-accident-injuries/guidelines-and-policies#gref).

Best practice note—21

Co-occurring spinal cord injury and amputation

Potential issues for a person with co-occurring spinal cord injury and amputation are:

- changed centre of gravity and impaired balance
- co-occurring and complex pain patterns e.g. neuropathic pain from the spinal cord injury and phantom limb pain
- additional activity limitations and participation restrictions e.g. transferring (particularly for someone with paraplegia and an upper limb amputation)
- mental health.

Additional supports, training and equipment are likely to be required.

Where there is a co-occurring spinal cord injury and amputation, the multidisciplinary team must include specialist rehabilitation spinal cord injury health professionals, as well as those experienced with amputation.

10.3.3 Traumatic brain injury

The literature review for the guidance revealed that people with lower limb amputations had a higher prevalence of cognitive impairment and concerns over their cognitive abilities (e.g. memory, concentration) than the general population [236-238]. The cognitive impairment was irrespective of age, or whether the amputation was related to a traumatic injury or disease [237]. This may be partly because a proportion of people sustain an undiagnosed brain injury at the time of the traumatic injury leading to the amputation. Other reasons may be medications for pain, such as opioids, influencing cognitive function [237].

Cognitive impairment in people with lower limb amputations is linked to poorer outcomes in their mobility, prosthesis use and maintaining independence after the amputation [236]. Involvement of a specialist brain injury team is appropriate.

Traumatic brain injury has significant implications for the person, and for the treatment and support they receive, particularly if the brain injury is not diagnosed. It also impacts the multidisciplinary rehabilitation team and the treatment they provide.

Best practice note—22

Co-occurring traumatic brain injury and amputation

Assessment and early diagnosis of traumatic brain injury or cognitive impairment will assist with meeting the person's needs in rehabilitation and their progress along the support pathway. A person with a brain injury may need alternative approaches to learning how to use their prosthesis (e.g. instructions, supervision, stepwise approach, memory prompts).

Where there is trauma involved, it is appropriate to investigate and screen for cognitive concerns and traumatic brain injury.

Resources—17

Information for healthcare professionals

Guidelines to assist in the screening, assessment and diagnosis of a mild brain injury and advice on recovery can be found at the following links:

- State Insurance Regulatory Authority (easy to read advice; available in other languages)
  See: www.sira.nsw.gov.au/theres-been-an-injury/injury-advice-centre/recovering-from-a-mild-brain-injury
- Ontario Neurotrauma Foundation (practical guidance for all stakeholders)
  See: braininjuryguidelines.org/concussion
- NSW Health Agency for Clinical Innovation
  See: aci.health.nsw.gov.au/__data/assets/pdf_file/0003/195150/Closed_Head_Injury_CPG_2nd_Ed_Full_document.pdf

11. Glossary

Carer

A person who provides supports to a person with a disability at no cost (generally a family member or friend) (can also be referred to as *informal support*, see below).

Case management (community-based)

Case management is a multidimensional and collaborative process. It involves a set of interventions for assessment, planning, coordinating and review of the options and services required to meet the client's health-related needs, and support them to reach their goals related to participation in life roles [239].

Coordinator

The person who ensures services are coordinated and provided to meet the participant's needs and scheme objectives in the Lifetime Care and Support Scheme and the Workers Care program. Works for icare with participants who have an external *case manager*, across the three phases of the support pathway, i.e. Recovery, Participation and Maintaining lifestyle and health (icare NSW).

Claims advisor

A case manager working for the Workers Insurance funding body. The case manager is responsible for coordinating all aspects of the worker's claim including medical treatment, care, payment of weekly benefits, compensation and other legal aspects.

Community living facilitator

A case manager working for icare with a focus on supporting participation and maintaining way of life for the participant. Works with participants in the Participation and Maintaining lifestyle and health phases of the support pathway, under the Lifetime Care and Support Scheme and the Workers Care program (icare NSW).

Co-morbid condition

An additional condition independent of and unrelated to the primary condition [36]. Examples are cancer or intellectual disability.

A related term is multi-morbidity, which is the experience of multiple chronic conditions at the same time

Co-morbidity and multi-morbidity can lead to interactions among conditions; between one condition and the treatment recommendations for another condition; and among medications prescribed

Co-morbidity and multi-morbidity may result in greater impacts on functioning, quality of life and risk of mortality than the sum of the individual effects that might be expected from these conditions [79].

Disability

An umbrella term for impairments, activity limitations or participation restrictions [240].

External case manager

A case manager who is not an employee of the funding scheme (Lifetime Care and Support, Workers Insurance). They are contracted to provide the community-based case management services to the person.

Facilitator(s)

External (environmental) or internal (personal) factors that positively influence the person's functioning and disability. Environmental factors include the physical (e.g. buildings), social (e.g. equipment funding policy and schemes) and attitudinal world (e.g. attitude of family, friends or health professionals). Personal factors are attributes of the person (e.g. motivation).

The opposite of a facilitator is a barrier, which is a factor that hinders the person's functioning and ability [240].

Formal supports

A task or work done by someone for another as a job or duty (paid). The support is usually organised or structured. Government, non-profit organisations and the for-profit sector usually provide the services. The person employed to perform the tasks is referred to as a support worker or attendant care worker, personal care assistant, domestic assistant, maintenance assistant or care worker [241].

Functioning

An umbrella term for body functions, body structures, activities and participation [240].

Funder

An organisation that provides money for a particular purpose, in some systems also called an insurer. In the context of this guideline, the funding is for treatment, rehabilitation and care costs. Example of funders: Lifetime Care and Support Scheme, Compulsory Third Party scheme, compulsory third party (CTP) insurer, Workers Care program, Workers Insurance scheme.

Informal support

Resources (goods, services, or a person who performs a task or work) that are inbuilt in the person's environment and enhance quality and security of life. Informal supports support the person when there is a need and may be reciprocated with different goods, services or tasks (unpaid). Informal supports are often provided by those in the person's network including family members or friends (who might be referred to as a carer), or members of a community (unpaid). The support is typically 'ordinary' and less formal, and may be ad hoc [241].

Multidisciplinary team

The term used in this guidance to refer to the team of health professionals who may provide rehabilitation treatment, guidance and support to the person (and their family) before the operation, after an amputation and throughout the person's life. A range of health professionals may be involved depending on the person's circumstances, and their progress and needs on the support pathway. Who is involved, and the timing and frequency of contact also varies. Health professional(s) who may be involved include the case manager, dietitian, exercise physiologist, general practitioner, medical specialist (e.g. orthopaedic surgeon, neurosurgeon, pain specialist), occupational therapist, physiotherapist, podiatrist, prosthetist, psychologist, rehabilitation specialist, social worker and vocational rehabilitation provider. In addition to the health professionals, the multidisciplinary team may also include a trained peer support worker.

Orthosis

An externally applied device used to support, align, correct or improve function of the movable parts of the body. Orthoses can be 'off the shelf', customised or fabricated.

Prosthetist or orthotist

Person who has completed an approved course of education and training and is authorised by an appropriate national authority to design, measure and fit prostheses and orthoses[242]). In Australia, there are competency standards for prosthetists and orthotists (see: www.aopa.org.au/publications/competency-standards).

Prosthesis, prosthetic device or product

Externally applied device used to replace wholly or partly an absent or deficient limb segment (NOTE: 'Prosthetics' refers to the science and art of treating people using prostheses.) [242]

Primary condition

The possible starting point for impairment, activity limitation or participation restriction [36]. The amputation itself may be the primary condition, for example, if it is a traumatic amputation (amputated at the time of the trauma). A primary condition may also be another condition that leads to an amputation, for example, a compound fractured femur with complications.

Rehabilitation case manager

A case manager working for icare with a focus on supporting continuing recovery and independence for participants after injury. Works with participants in the Recovery phase of the support pathway, under the Lifetime Care and Support Scheme and the Workers Care program (icare NSW).

Residual limb, *see stump*

Secondary condition

An additional condition that presupposes the existence of a primary condition. It is distinguished from other health conditions by the lapse in time from the acquisition of the primary condition to the occurrence of the secondary condition [36].
An example is an ulcer on the amputated limb stump. The amputation itself is considered the secondary condition when a primary condition (such as complications from a fracture) leads to an amputation.

Social insurance scheme

A public insurance program that provides protection against various risks (e.g. sickness, disability, old age, unemployment). In the context of this guidance, the social insurance scheme refers to government organisations that collect a levy from either employers or motor vehicle car owners, which pays for the treatment, rehabilitation and care for people injured in motor vehicle crashes or at work.

Support worker

A paid person who assists people to perform tasks of daily living so the person can participate in social, family and community activities in their home and community.

A support workers may also be referred to as an attendant care worker, disability worker, aged care worker, community worker, homecare worker, care worker or paid carer.

Stump[1]

The portion of the arm or leg remaining after an amputation; may be referred to as the residual limb.

Valued others

May include the person's family, friends and carers [26].

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[1] There is continuing discussion on the most appropriate term for the residual limb. 'Stump' is used in this document, based on advice from people with lived experience.

12. Abbreviations

CTP	Compulsory Third Party
GP	General practitioner
icare	icare (Insurance & Care NSW)
NSW	New South Wales
LTCS	Lifetime Care and Support Scheme
WHO	World Health Organization

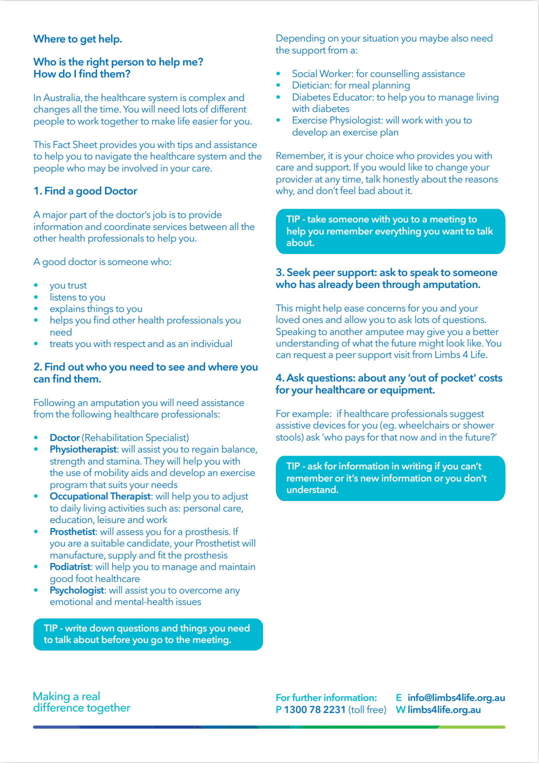
13. Resources

Understanding the health care system

Permission to reproduce and include in the guidance was granted by Limbs4Life on 23 December 2020.
www.limbs4life.org.au/resources

Fact Sheet #01

Understanding the healthcare system



Where to get help.

**Who is the right person to help me?
How do I find them?**

In Australia, the healthcare system is complex and changes all the time. You will need lots of different people to work together to make life easier for you.

This Fact Sheet provides you with tips and assistance to help you to navigate the healthcare system and the people who may be involved in your care.

1. Find a good Doctor

A major part of the doctor's job is to provide information and coordinate services between all the other health professionals to help you.

A good doctor is someone who:

- you trust
- listens to you
- explains things to you
- helps you find other health professionals you need
- treats you with respect and as an individual

2. Find out who you need to see and where you can find them.

Following an amputation you will need assistance from the following healthcare professionals:

- **Doctor** (Rehabilitation Specialist)
- **Physiotherapist**: will assist you to regain balance, strength and stamina. They will help you with the use of mobility aids and develop an exercise program that suits your needs
- **Occupational Therapist**: will help you to adjust to daily living activities such as: personal care, education, leisure and work
- **Prosthetist**: will assess you for a prosthesis. If you are a suitable candidate, your Prosthetist will manufacture, supply and fit the prosthesis
- **Podiatrist**: will help you to manage and maintain good foot healthcare
- **Psychologist**: will assist you to overcome any emotional and mental-health issues

TIP - write down questions and things you need to talk about before you go to the meeting.

Depending on your situation you maybe also need the support from a:

- Social Worker: for counselling assistance
- Dietician: for meal planning
- Diabetes Educator: to help you to manage living with diabetes
- Exercise Physiologist: will work with you to develop an exercise plan

Remember, it is your choice who provides you with care and support. If you would like to change your provider at any time, talk honestly about the reasons why, and don't feel bad about it.

TIP - take someone with you to a meeting to help you remember everything you want to talk about.

3. Seek peer support: ask to speak to someone who has already been through amputation.

This might help ease concerns for you and your loved ones and allow you to ask lots of questions. Speaking to another amputee may give you a better understanding of what the future might look like. You can request a peer support visit from Limbs 4 Life.

4. Ask questions: about any 'out of pocket' costs for your healthcare or equipment.

For example: if healthcare professionals suggest assistive devices for you (eg. wheelchairs or shower stools) ask 'who pays for that now and in the future?'

TIP - ask for information in writing if you can't remember or it's new information or you don't understand.

Making a real
difference together

For further information:
P 1300 78 2231 (toll free)
E info@limbs4life.org.au
W limbs4life.org.au

Skincare tips for amputees

Permission to reproduce and include in the guidance was granted by Limbs4Life on 23 December 2020. The "Skincare tips for amputees" flyer is available on the Limbs4Life website: www.limbs4life.org.au/resources

Limbs4Life
Empowering Amputees

Skincare Tips for Amputees

CHECK your stump daily for marks or skin breakdowns using a hand mirror

STOP wearing your prosthesis if you have pain or discomfort

WEAR safe and comfortable footwear at all times

SEEK advice from your healthcare provider if you notice any changes to your skin

TURN OVER FOR SKINCARE CHECKLIST

Don't wait until it's too late.
Act immediately.

CHECKLIST

I need to seek medical attention if my stump:

- Has new red marks that do not fade after 15 minutes
- Is discharging blood, fluid or pus
- Temperature feels unusually cold or hot

I need to contact my prosthetist if:

- My prosthesis is not fitting properly - too tight/too loose
- My stump socks have worn thin/have holes
- My liner has started to tear/split/wear thin
- My prosthesis feels unsafe/unsteady
- My prosthesis sounds, feels, looks different
- My 12 month review is due

1300 78 2231
limbs4life.org.au

Hygiene for amputees

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www.limbs4life.org.au/resources

Hygiene for amputees from Limbs4Life

Limbs4Life
Empowering Amputees

Hygiene for Amputees

Clean skin
↓
Healthy stump
↓
Less pain
↓
More active

TURN OVER FOR FOR DAILY TIPS

Daily tips to keep you on the go.

DAILY

- Wash stump in soapy water, rinse and dry well
- Change stump socks and liners, more often in warm weather
- Wash stump socks and liners after use
- Wipe your socket with a clean damp cloth

PROTECT

- Dry your skin well before putting on your prosthesis
- Avoid wearing wet or damp socks and liners

SEEK

- Advice from your healthcare professional if you notice any changes to your skin

1300 78 2231 (Toll Free)
limbs4life.org.au

Tip sheet TSV001
Information for prosthesis
users and their family

Limb prosthesis maintenance

You're the user of your prosthesis and you depend on things working to do what you want to do. Think about routine maintenance and repairs for your prosthesis like you do with parts of your body (like your teeth and the maintenance and repairs by your dentist).

You need to go to the prosthetist to have the regular maintenance checks on your prosthesis, and then also have the prosthetist do the repairs when there is a problem. There are also conditions under the prosthesis warranty that you must keep, which means you can't try to repair or fix your prosthesis yourself.

If you look after your prosthesis and do the basic maintenance outlined below, it helps to prevent inconvenient breakdowns. Breakdowns can put you at risk.

You must routinely take the prosthesis to the prosthetist for a check, maintenance and review at LEAST once a year. Small adjustments can make a big difference.

Ask your prosthetist to send you a reminder to make an appointment when the yearly or 6-monthly maintenance and review is due.

You also visit the prosthetist for repairs.

Your funder (e.g. icare) has already paid for your prosthesis warranty and annual service plan with the prosthetist at the time of purchase.

There are basic tasks to care for your prosthesis that you need to do, so it will work well and last longer. **As the owner of the prosthesis, you have these responsibilities.**

1. First you need to:

- Have a basic understanding of how the prosthesis works. Ask your prosthetist to explain.
- Pick the same day every week to routinely check for any signs of wear and tear of your equipment, e.g. cracking in the socket, damage or loose parts, tears in the liner or sock, worn rubbers on a walking aid.
- Keep your prosthesis clean and dry to prevent build-up of dirt and bacteria.
- Prevent water damage unless your prosthesis is waterproof.
- Store your prosthesis properly when you are not wearing it. Put it somewhere safe, so it isn't bumped. When you take your prosthesis off, don't leave it in a hot environment such as in the sun in the car, or near an oven or radiator.

2. Make an appointment with the prosthetist immediately if:

- There is something loose or damaged
- Your prosthesis is not working as it should, or something doesn't feel right
- You think there may be something wrong
- The socket is not fitting (if its loose or too tight)
- There is damage to any part of the prosthesis
- There are new or unusual noises
- You have redness and pressure areas, injuries or more pain from using your prosthesis

Try to reduce or avoid using your prosthesis until the appointment with the prosthetist. In the meantime, you could ask your prosthetist about temporary solutions.

3. General cleaning

Prosthesis

DON'T

- Clean any of the prosthetic components
- Adjust screws, bolts, hinges or other parts of the prosthesis or attempt to repair it yourself. You will breach the warranty conditions and cause permanent damage.
- Add or coat the socket with anything, e.g. talcum powder, packing material

Prosthesis

DO

- Wipe down the outside and inside of the socket, and the outside along the whole prosthesis with a soft damp cloth with mild soap OR alcohol-based cleanser if advised by the manufacturer.
- Be careful not to wipe or get wet the mechanisms or electronic components.

For upper limb prosthesis only

- If myoelectric—follow manufacturer's instructions to care for the battery.

Don't carry heavy things or hang heavy items off the fingers of the prosthetic device.

Liner maintenance

DO

- Wear a clean liner every day.
- Wash your liner daily with mild soap and water.
- Pat dry your liner with a towel and leave to air dry overnight. Do not dry the liner in the sun, clothes dryer or in front of a heater.
- Keep the liner free from dirt, fluff and dust, ink from pens or newspapers, lipstick.
- Check your liner for tears.

Sock maintenance

DO

- Wear a clean sock every day.
- Stump socks can be machine washed but others need to be washed by hand. Check with the manufacturer. If the sock is NOT machine washable:
    - Wash your sock by hand with soapy water.
    - Avoid twisting, wringing out or rubbing wet socks as they will lose shape.
    - Roll out the sock in a towel to remove extra water dry and hang up to dry. Do not dry the sock in the clothes dryer or in front of a heater.
- Check for loss of shape.

4. Develop a plan for when something breaks down

Ask your prosthetist to give you some ideas on how you can plan for what you should do when something breaks down. For example, know: `

- Whether there are loan components or limbs available
- The options when you are travelling or on holidays and away from your usual prosthetist
- How often specific parts need replacing, and the procedure (e.g. pre-ordering). If you 'work' your prosthesis hard because of the nature of your work, sport and daily routine, ask your prosthetist if this affects how often parts need replacing.
- If you can't have an appointment to see your prosthetist, ask if you can have a telehealth consultation.

Tips on managing pain and limb amputation

It takes a team to work out the best treatment for you. The team includes you, your family, your general practitioner (GP) and your rehabilitation team.

Ask and talk about pain **before** your operation to amputate and **after**—it's important that you and your family know and understand that phantom limb pain is real and common. At any stage over the years, the pain can change, get worse or resolve, or a different pain can start.

The rehabilitation team and your GP should thoroughly assess and regularly review your pain.

Talk about the different treatments and what might be good for you to try. Aim for a combination of treatments and include **non-drug** treatments.

Develop and write down a pain management plan with a combination of strategies, to share between you and your family, your rehabilitation team and your GP.

Keep checking on your pain and work with your rehabilitation team and GP to review strategies to manage your pain, progress and quality of life.

You should be referred to a pain specialist if needed.

A lot of people have pain before and after limb amputation. The pain is real and different for each person. The research gives different percentages on how many people experience different types of pain, but most people with an amputation (around 68% to 86%) experience pain at some stage.

Someone with a limb amputation might have a pain such as:

1. Painful sensations in the area of the missing limb ('phantom limb pain'). It's complicated, but researchers think phantom limb pain happens because the amputation causes the person's brain to reorganise the 'map' that helps them recognise body sensations in the missing limb. There is also 'phantom limb sensation' which is not painful. The person might talk about feeling itchy or cold in the missing limb, or feeling like it is a different shape. This type of sensation is normal and does not need to be treated.
2. Hot, burning, electric, pins and needles, shooting pain ('neuropathic pain')
3. Aching, sharp or dull posture- or movement-related pain ('musculoskeletal pain')
4. Pain in the part of the limb left from the surgery, from swelling, a fall, bruising or infection ('stump pain').

Phantom limb pain

Researchers think phantom limb pain may be influenced by:

- The person being very anxious before the operation or stressed after the operation or not adjusting to the amputation. Psychological support would help in any of these situations.
- Wearing the prosthesis as soon as possible and as often as possible, which might help the person's brain to sort out the brain 'map'. The brain gets the chance to adapt (called 'neuroplasticity').

There are different treatments for phantom limb pain, but no one type of treatment can fix the pain for everyone (refer to the Guidance on the support pathway for people with a limb amputation and trialling a prosthesis).

Musculoskeletal pain

Low back pain is a common experience for many people with a lower limb amputation. It depends on their day-to-day activities and work. For people with lower limb amputations, the extra effort and fatigue associated with the prosthesis, uneven postures and movements means they are likely to experience pain.

Treatment

Knowing the best treatment for each person's pain is tricky because it can be different. It can take time for the person and their health and rehabilitation team to work out the right treatment.

Some treatments that may be helpful are:

- education on pain
- mirror therapy (using a mirror image to 'trick' the person's brain), using movement and stroking, and sometimes virtual reality
- relaxation techniques (mental imagery, progressive muscle relaxation, meditation)
- specific exercise strategies for posture and pacing
- tactile desensitisation (self-administered massage and tapping)
- acupuncture
- TENS (transcutaneous electrical nerve stimulation)
- psychological treatments
- drugs for neuropathic pain e.g. anti-seizure drugs; opioids (avoid when possible)
- surgery (e.g. targeted muscle reinnervation where a good nerve is transferred to a different part of the body where the nerve is not working)
- injections (e.g. ozone injection, nerve block)
- nerve stimulation.

Resources

Australian Pain Management Association
www.painmanagement.org.au

ACI Pain Management Network
https://aci.health.nsw.gov.au/chronic-pain/for-everyone

Health Engine
healthengine.com.au/info/phantom-limb-pain

Limbs4Life
www.limbs4life.org.au/steps-to-recovery/managing-pain

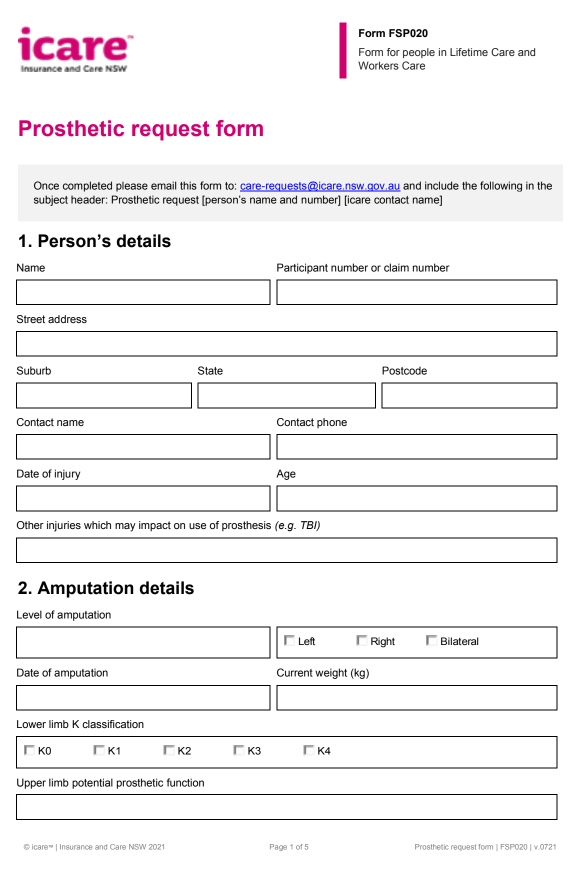
Enable
www.enable.health.nsw.gov.au/about/publications/fact-sheets/managing-pain

Documentation related to requests and funding

Prosthetic Request Form for Lifetime Care and Workers Care available on the icare website

https://www.icare.nsw.gov.au/practitioners-and-providers/forms-and-resources/lifetime-care

Go to > Equipment and maintenance accordion



icare™ Insurance and Care NSW

Form FSP020

Form for people in Lifetime Care and Workers Care

Prosthetic request form

Once completed please email this form to: care-requests@icare.nsw.gov.au and include the following in the subject header: Prosthetic request [person's name and number] [icare contact name]

1. Person's details

Name

Participant number or claim number

Street address

Suburb

State

Postcode

Contact name

Contact phone

Date of injury

Age

Other injuries which may impact on use of prosthesis *(e.g. TBI)*

2. Amputation details

Level of amputation

☐ Left ☐ Right ☐ Bilateral

Date of amputation

Current weight (kg)

Lower limb K classification

☐ K0 ☐ K1 ☐ K2 ☐ K3 ☐ K4

Upper limb potential prosthetic function

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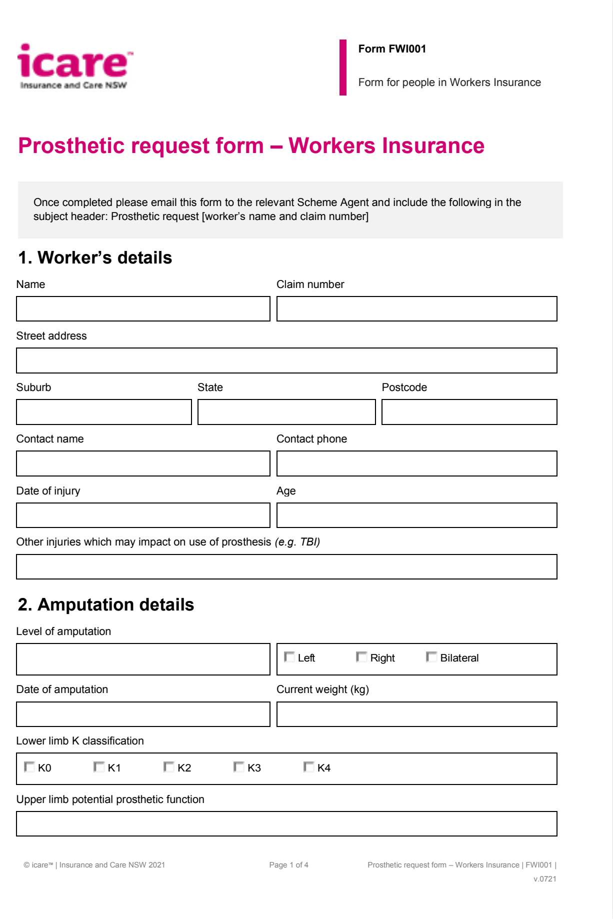
Prosthetic Request Form for Workers Insurance available on the icare website

www.icare.nsw.gov.au/practitioners-and-providers/forms-and-resources/workers-insurance

Go to > Other forms for healthcare professionals



icare™ Insurance and Care NSW

Form FWI001

Form for people in Workers Insurance

Prosthetic request form – Workers Insurance

Once completed please email this form to the relevant Scheme Agent and include the following in the subject header: Prosthetic request [worker's name and claim number]

1. Worker's details

Name

Claim number

Street address

Suburb

State

Postcode

Contact name

Contact phone

Date of injury

Age

Other injuries which may impact on use of prosthesis *(e.g. TBI)*

2. Amputation details

Level of amputation

☐ Left ☐ Right ☐ Bilateral

Date of amputation

Current weight (kg)

Lower limb K classification

☐ K0 ☐ K1 ☐ K2 ☐ K3 ☐ K4

Upper limb potential prosthetic function

© icare™ | Insurance and Care NSW 2021 Page 1 of 4 Prosthetic request form – Workers Insurance | FWI001 | v.0721

14. Appendices

Appendix 1
Summary for the best practice support pathway

There is a separate document ‘Summary for the best practice support pathway for people with a limb amputation’. The document includes an explanation of the support pathway, all the recommendations, best practice notes and resources.

Refer to the icare website to download a copy www.icare.nsw.gov.au

icare
Insurance and Care NSW

Summary for the best practice support pathway for people with a limb amputation
(and trialling a prosthesis)
2021

The support pathway image and explanation

- The recommendations
- Best practice notes
- Resources

Appendix 2
External reviewers of the draft guidance

There were 10 reviewers, both Australian and international. Four reviewers elected to remain anonymous. Some reviewers also had lived experience of limb amputation.

Name	Position	Organisation
Alexandra Piepers	Senior Rehabilitation Physiotherapist	Sutherland Hospital, NSW
Anne Haron	Occupational Therapist	Greenwich Occupational Consultancy
Anonymous	Orthotist/Prosthetist	Working internationally in assistive technology
Anonymous	Service Provider	New Zealand
Anonymous	Rehabilitation Advisors	Three Compulsory Third Party insurance companies
Anonymous	Prosthetist	In private practice and advising the National Disability Insurance Agency
Lloyd Walker	Rehabilitation Engineer	Director Assistive Technology Markets, National Disability Insurance Agency
Natasha Layton	Senior Research Fellow	Rehabilitation, Ageing and Independent Living Research Centre (RAIL) Monash University
Sally Cavenett	Director, Orthotics Prosthetics, South Australia	Southern Adelaide Local Health Network, South Australia Health
Susan Arnold	Occupational Therapist	Private practice

Appendix 3
Reviewers of the limb prosthesis maintenance information sheet

Thank you to the Limbs4Life National Amputee Advisory Council who have lived experience, and who reviewed and provided feedback on the draft of the limb prosthesis maintenance information sheet:

- Andrew Fairbairn
- Kylie Franson
- Melissa Noonan
- Ren Gallet
- Sara Shams

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Notes

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