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Insurance and Care NSW

Summary for the best practice support pathway for people with a limb amputation

(and trialling a prosthesis)

2024

Summary for the best practice support pathway for people needing prosthetic limbs

The Summary for the best practice support pathway for people needing prosthetic limbs provides a summary of the recommendations, best practice notes and resources included in the full guidance document.

The support pathway

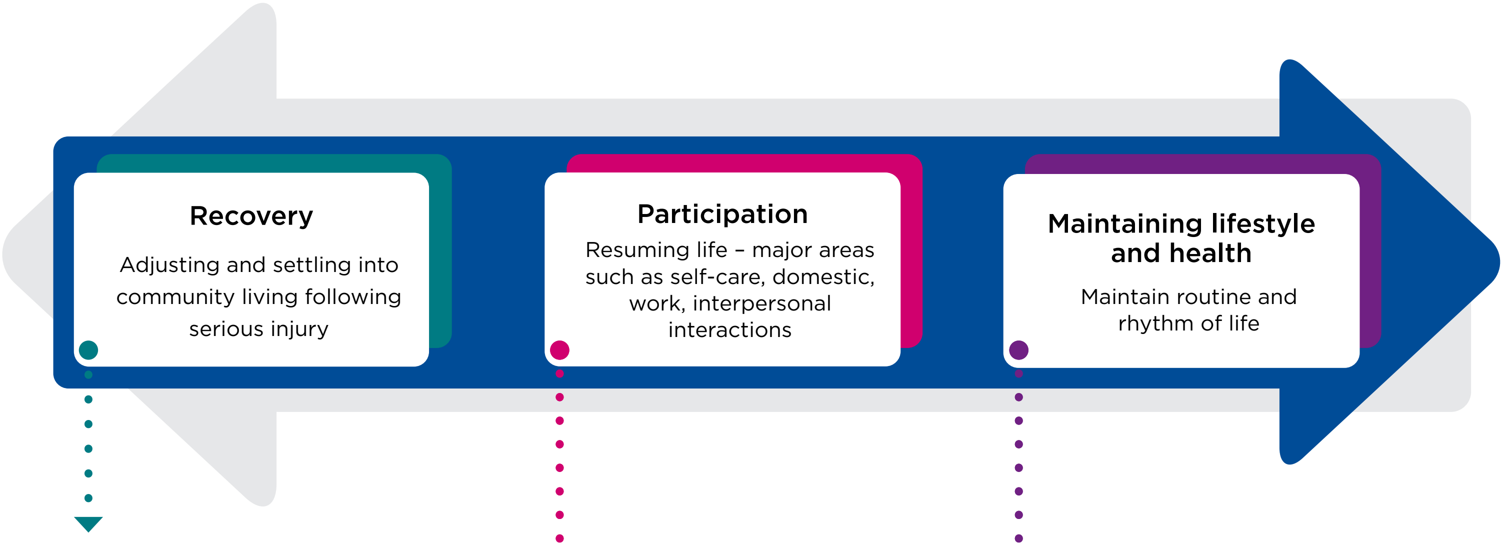
The support pathway relates to the period after amputation. Understanding the pathway and describing the supports needed, provides direction for action by all involved including health professionals, service providers, funders of prosthetics and rehabilitation services and insurance regulators. Importantly this guidance also assists the person with the amputation, strengthens their understanding and thereby empowers them, their families and carers with their expectations.

There are three phases in the support pathway adapted from the My Plan toolkit available on the icare website www.icare.nsw.gov.au. The phases are:

- Continued recovery,
- Participation,
- Maintaining lifestyle and health.

A person may experience a life event (e.g., becoming a parent, changing jobs, experiencing a co-occurring health condition) which indicates that they may require changes to their supports and so 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

8.1 *Integrating and coordinating services and supports*

	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*

	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*

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

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: https://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

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

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*

	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)

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: https://www.icare.nsw.gov.au/injured-or-ill-people/motor-accident-injuries/guidelines-and-policies

8.7 *Peer support*

	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*

	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

	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.

	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

	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

	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

	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: opedge.com/Articles/ViewArticle/2012-12_03 (article from The O&P Edge)

8.13 Body weight and fitness

	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: https://www.health.gov.au/topics/overweight-and-obesity/bmi-and-waist

8.14 Managing stump (residual limb) complications

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*

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.

8.17 *Communication*

Communication between stakeholders

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*

	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*

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—see: australian.physio/sites/default/files/APATelehealthGuidelinesCOVID190420FA.pdf (Australian PhysiotherapyAssociation)
- psychologists—see: www.psychology.org.au/for-the-public/Medicare-rebates-psychological-services/Medicare-FAQs-for-the-public/Telehealth-services (Australian Psychological Society)
- rehabilitation physicians—see: www.racp.edu.au/fellows/resources/digital-health (The Royal Australasian College of Physicians)

9. Connected health issues

9.1 *Psychosocial wellbeing and mental health conditions*

	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 6)	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 Section 8.11 Lifelong monitoring)	Consensus

9.2 *Body image*

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

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

	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*

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 amputeess)*
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

10.1 *Burns*

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

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

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

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

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

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.

Insurance and Care NSW

Tip sheet TSV002
Information for prosthesis users and their family

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/chronic-pain

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 icare.nsw.gov.au