Care of the Person following Amputation

Minimum Standards of Care
Care of the person following amputation: minimum standards of care has been specifically written for healthcare professionals and health services to outline the minimum standards of care that health services in NSW are expected to provide for people facing the prospect of, or those already living with, limb loss (the person).

This interactive PDF has been designed to provide you with the key information to support implementation of the standards in your service.

The document comprises 12 individual care standards focusing on both service- and person-based standards. These can be accessed through the “Standards” button located on the top menu or by clicking on the wheel icon. Additional information can be viewed by clicking on each standard.

Access the original document, containing additional information, anytime through this icon.

A useful tool and a guide is available through the “Practical tools and guides” button. Health services can use the self-assessment tool to evaluate their existing service and identify areas for improvement necessary to meet the standards of care.

The guide contains recommendations on the use of a removable rigid dressing in patients who have undergone a transtibial amputation.

The minimum standards of care are not intended to replace informed clinical judgment nor prescribe how a healthcare service should meet these standards.
Annually in NSW, more than 2000 amputation procedures are performed. Two-thirds of people who have amputation surgery are over 60 years of age. Amputation is most commonly due to peripheral vascular disease - often secondary to the long-term effects of diabetes - as well as trauma and tumours. Rarely, children are born with the absence of a limb. Although the number of amputation surgeries are relatively small, the changes to body structures and function are significant and lifelong.

With the significant impact of amputation, it is important that minimum standards of care are developed to ensure that all residents of NSW obtain consistent high standards of care and thereby ensure their needs are met at all stages of the lifelong journey of living with limb loss.
Standards

**Service-based standard**
Standards to ensure a consistent service is provided to the person

**Person-based standard**
Standards relevant to clinical care of the person

The 12 minimum standards of care for the person undergoing amputation.

- **S1.** Care coordination
- **S2.** Comprehensive care
- **S3.** Counselling and psychological support
- **S4.** Peer support
- **S5.** Falls prevention
- **S6.** Discharge planning
- **S7.** Specialist paediatric care
- **S8.** Upper limb amputation
- **P1.** Care of the residual limb
- **P2.** Education across all stages of care
- **P3.** Pain
- **P4.** Special consideration for specific populations
Care for the person is coordinated across multiple specialties and supported by interdisciplinary assessment.

A specialist interdisciplinary team provides coordinated care throughout all care phases for the person. The care requirements are complex, and coordination of multiple medical, surgical and rehabilitation specialties is required. Across all phases of care, interdisciplinary team assessment should be utilised to support development of a comprehensive treatment plan. This treatment plan is developed in collaboration with the person and their valued others, and guides care from pre-surgical to post-surgical, and rehabilitation phases. Care is coordinated and all members of the clinical team contribute to the care plan and treatment program.

The composition of the team will vary depending on the unique needs of the person and the phase of their care. Each phase of care must have oversight from a clinician experienced in the management of amputation or limb loss.
Applying the standard in practice

- A pre-amputation consultation is conducted for all planned amputations, with the surgeon and representatives of the rehabilitation team involved with rehabilitation care after the surgery.
- When amputation occurs unexpectedly, e.g. due to trauma, the surgical team refers the person to the rehabilitation service.
- The person who has undergone an amputation knows who and how to access their specialist teams in order to review their changing needs and access ongoing rehabilitation care as required.
Quality measures

**System Measurements**

- All health services that perform amputations have local processes and structures in place to support the provision of interdisciplinary care to people undergoing amputation.
- Amputee services demonstrate evidence of communication strategies between clinical services involved in amputee care (including surgical, rehabilitation, endocrinology, orthopaedic and vascular streams), primary care and community health, and community support services.
- Pre-surgical amputation consultations are attended by rehabilitation providers with expertise in the management of amputation.
- Information on the proportion of persons undergoing amputation referred to rehabilitation are collected by services performing amputations.

**Patient Measurements**

- Patient reported measures.
- The person and their valued others are aware of the different clinical specialities involved in their care.
Context

A comprehensive care plan tailored to the needs of the individual is developed and updated throughout the care journey. The care plan should include a thorough, integrated and interdisciplinary person-centred assessment that outlines specific interventions required. With the exception of unplanned amputations, the care plan is developed pre-operatively, and with input from the rehabilitation team.

Interventions that may assist with maintenance of current function and prevention of secondary complications should be commenced prior to surgery where possible and continue through the care journey.
Applying the standard in practice

- A comprehensive assessment that evaluates the person’s physical condition (including body system review), nutrition, pain, cognitive function, psychological status and social support systems is completed.
- The person’s valued goals and priorities, including independence, preferred activities and participation are documented prior to surgery.
- The care plan includes information on the person’s accommodation, living arrangements and environment.
- The comprehensive assessment and care plan documented in the pre-surgical phase of care is reviewed and updated throughout the care journey and includes care of the residual limb.
- Access to a specialist interdisciplinary team is available for all persons undergoing amputation.
- Planning for life after amputation begins once the decision to amputate is made.
- Except in cases of extreme urgency, surgical interventions consider the potential for future rehabilitation and prosthetic use.
- Rehabilitation addresses the person’s changing function and needs.
- There is information provided and discussion regarding rehabilitation options including non-prosthetic, prosthetic and osseointegration management.
Quality measures

System Measurements

- Amputee services demonstrate evidence of communication strategies between clinical services involved in amputee care (including surgical, rehabilitation, endocrinology, orthopaedic and vascular streams) and primary care and community health providers.

- Collection of data relating to the use of evidence-based interventions is supported (e.g. proportion of transtibial amputees using a rigid dressing).

Patient Measurements

- The person is involved in developing their care plan and is informed of the outcome of all assessments.
S3. Counselling and psychological support

Context

Counselling and psychological support is available to the person and their valued others pre-operatively and continues as part of lifelong management. Experienced clinical counselling and psychological support is available to assist with issues such as adjustment and pain management from the acute phase, and throughout lifelong management.

Psychosocial issues are evaluated and addressed as part of the overall treatment plan and reviewed regularly throughout the care journey.
Applying the standard in practice

- A psychological assessment is completed in the pre-operative phase.
- Psychosocial functioning is assessed at each phase of management (from acute to rehabilitation, and beyond). A particular focus on depressive, anxiety and post-traumatic stress disorder (PTSD) symptoms supports structured interventions for any problems identified.
- Counselling and psychological interventions explore effective coping strategies for the individual. Valued others are included in the interventions as required.
- Screening for depression, anxiety, sexual difficulties, substance abuse and pain occurs during the care journey and specific interventions offered if required.
S3. Counselling and psychological support

Quality measures

**System Measurements**

- Amputee services support the provision of specific interventions for depression, anxiety, sexual difficulties, substance abuse and pain across the care journey.
- Proportion of persons screened for depression, anxiety, sexual difficulties, substance abuse and pain.
- Psychosocial assessment is conducted during each phase of care.

**Patient Measurements**

- Evidence of the use of validated tools for screening and assessment.
S4. Peer support

Referral is offered to a managed peer support program

Context

Referral to a managed peer support program is offered either pre- or post-amputation. It is emotionally challenging to adjust to an amputation. Peer support allows the person to speak directly with someone who has shared their experience and can provide a valuable resource for the person and their valued others during the early stages of their recovery and/or throughout their lifetime.

Peer support can:

- assist people to adapt to the challenges of amputation
- promote social inclusion
- provide access to information and resources
- help reduce fear, anxiety, depression and emotional distress
- assist people to re-engage with their communities.
S4. Peer support

Referral is offered to a managed peer support program

Applying the standard in practice

Referral to a managed peer support program is made as early as possible, in line with individual needs and wishes. Referral to a managed peer support program is important given the nature of peer support discussion and that people seeking support are often vulnerable.

Managed peer support programs ensure that peer support volunteers:

- 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-visitiation 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.
S4. Peer support

Referral is offered to a managed peer support program

Quality measures

System Measurements

- Amputee services demonstrate linkages to managed peer support program.
- Proportion of persons accessing managed peer support services annually.

Patient Measurements

- Patient reported measures.
S5. Falls prevention

Education and training on falls prevention and safety, including how to get up from the floor in the event of a fall is provided to persons and their valued others.

Context

All health professionals and care providers involved in amputee care are aware of the increased risk of falls for this population, particularly for those with lower limb amputation. Strategies to minimise the risk of falling both with and without a prosthesis are initiated in the immediate post-operative phase and reviewed throughout the course of care.

Limb protection is emphasised, especially during the early phases when the risk of falling is greatest and awareness of the amputation may be variable. External protective devices, such as rigid removable dressings may be used to increase protection of the residual limb.
S5. Falls prevention

Education and training on falls prevention and safety, including how to get up from the floor in the event of a fall is provided to persons and their valued others

Applying the standard in practice

- All persons are assessed using a valid falls risk screening tool and any identified risks are addressed.
- A balance and falls prevention exercise program delivered by a physiotherapist is offered to people at risk of falls.
- Gait training and provision of appropriate gait aids commence as early as possible.
- Rigid removable dressings (RRD) are used for transtibial amputees to help protect the limb in the event of a fall. *(See Standard P1).*
- All persons receive a home safety review delivered by an occupational therapist.
- The person is encouraged to maintain an active lifestyle.
- Risks are addressed and educational opportunities are provided both formally and informally on an ongoing basis.
Quality measures

System Measurements
- Completion of falls risk screening tool.
- Processes exist to allow early application of RRDs in transtibial amputations.
- Access to balance and falls prevention training programs.
- Falls rates.

Patient Measurements
- There is documented evidence of the use of RRDs for transtibial amputees.
- Patient reported measures.
S6. Discharge planning

Discharge planning and transfer of care arrangements commence as early as possible with communication between all key stakeholders.

Context

The person is supported in their ongoing management through discharge arrangements and follow-up services that reflect their individual rehabilitation goals.

Frequently the care pathway for the person varies between admitted and non-admitted care. The care pathway may not be continuous, with a period of time at home prior to rehabilitation with the prosthesis. At any point in the care journey, it is crucial that the person and their valued others are aware of the next steps in the process, and the lifelong nature of their care needs. Knowledge of service re-entry points and triggers for prosthetic review should be clearly communicated.
Applying the standard in practice

- Discharge recommendations and transfer of care plans are provided in writing to the person and any significant others involved in their ongoing care. Providing the discharge and ongoing care plan in advance gives the person and their valued others an opportunity to discuss any areas of the plan that they do not understand. This helps to maximise discharge safety and supports continuity of care.

- Each person has a designated contact for the service who is responsible for coordinating their rehabilitation and discharge planning. The contact person is named, and contact details provided at the initial entry point to the service.

- When transferring to another service, a new contact person is notified of the impending transfer and their contact details are provided.

- When the initial post-operative rehabilitation goals are met, the person is provided with a summary of their rehabilitation progress together with contact details for follow-up and re-entry to the service, and a follow-up plan.

- Follow-up occurs regularly in the initial period e.g. fortnightly/monthly for a few months, then 3-monthly, then 6-monthly. Once the residual limb has stabilised, follow-up should occur, at minimum, on an annual basis. This plan may vary depending on the needs of the person.

- Follow-up is lifelong.
S6. Discharge planning

Discharge planning and transfer of care arrangements commence as early as possible with communication between all key stakeholders.

Quality measures

**System Measurements**

- Proportion of amputees provided with a discharge plan at separation from inpatient services.
- The service has a documented process for providing designated contact details at point of entry to the service.
- A documented follow-up pathway exists for the service.

**Patient Measurements**

- The person knows who is their designated contact for the service.
- The person received a discharge report.
- The person received a follow-up plan at completion of the initial post-operative rehabilitation period.
S7. Specialist paediatric care

A child with a congenital limb loss or limb difference requires specialist care including access to a specialist Paediatric Limb Loss service.

Context

All children with a congenital limb loss or amputation should have access to a specialist paediatric team. The team should include a psychologist, and access to a play therapist (Figure 2). In the case of a congenital limb difference, referral to a geneticist should occur as soon as the limb difference is detected.

Figure 2. In addition to a surgeon and rehabilitation team, a wider group of services are recommended for children with a congenital limb loss or amputation.
A child with a congenital limb loss or limb difference requires specialist care including access to a specialist Paediatric Limb Loss service.

Applying the standard in practice

- Upon detection of congenital limb loss (and antenatally, if indicated), valued others (to the child) are referred to their local genetics service for advice on diagnosis and to one of the Sydney Children’s Hospital Network (Westmead or Randwick) limb clinics for antenatal counselling and management.

- Where surgery may be helpful in improving functional outcomes for congenital limb loss, a discussion about best management is held with valued others, a senior surgeon experienced in the field, a rehabilitation paediatrician, prosthetists and relevant allied health staff to support valued others to make an informed decision.

- All children under the age of 12 years with limb loss have access to a multidisciplinary team where all team members are experienced in paediatrics (Westmead and Randwick).

- For acquired amputation in childhood, contact is made prior to surgery with a paediatric surgeon (generally orthopaedic) or rehabilitation paediatrician with expertise in surgical strategies particular to children. Contact is also made with the paediatric rehabilitation team for pre-amputation counselling, and treatment is discussed. The paediatric pain team is available to advise on pre-amputation pain management.
S7. Specialist paediatric care

A child with a congenital limb loss or limb difference requires specialist care including access to a specialist Paediatric Limb Loss service.

Applying the standard in practice (cont’d)

- For adolescents (13–18 years), particularly those who have reached skeletal maturity in the affected limb, early contact with the local adult clinic is facilitated to aid with transition. A shared model is an option, particularly for those who have difficulty accessing Sydney. The paediatric clinic remains available up to 18 years but can be used in consultation.

- Adolescents transitioning to adult services are able to maintain their current prosthetic provider which aids the transition between specialist clinics and gives options for the person. (See Standard P4 – section Transition to adult services)

- Young people with limb loss have access to support so they can participate in sport and physical activity, including sport-specific prosthetic strategies.
S7. Specialist paediatric care

A child with a congenital limb loss or limb difference requires specialist care including access to a specialist Paediatric Limb Loss service.

Quality measures

System Measurements

- Service availability at tertiary clinic.
- There is a documented process for access and referral to both local genetics service and tertiary limb service for antenatal clinics.
- There is documented evidence of contact with both local genetics and tertiary limb services prior to birth.
- There is documented evidence of face-to-face contact at one of the paediatric clinic before 3 months of age.

Patient Measurements

- Patient reported measures.
- Evidence of participation in physical activity.
- Age of entry to the service for children with congenital limb absence.
The person who has experienced an upper limb amputation requires access to a specialist upper limb amputee rehabilitation service.

**Context**

Each person with an upper limb amputation has access to a specialist team that includes a rehabilitation physician, prosthetist and occupational therapist with experience in upper limb rehabilitation (Figure 3). In addition, it is also highly desirable to have access to a physiotherapist, social worker and psychologist experienced in managing upper limb amputation.

Figure 3. In addition to the surgeon and rehabilitation team, access to specialists with experience in rehabilitation for upper limb amputation is recommended.
S8. Upper limb amputation

The person who has experienced an upper limb amputation requires access to a specialist upper limb amputee rehabilitation service.

Applying the standard in practice

- Amputee services have documented links with specialist upper limb amputee services.
- Training by an occupational therapist with experience in upper limb rehabilitation is provided to the person, including:
  - Education and functional retraining in non-prosthetic management of activities of daily living (ADL) which may include dominance retraining, one-handed ADL techniques, and the use of adaptive equipment
  - Bimanual functional training using a prosthesis.
- Occupational therapy training and team involvement is essential when a new prosthesis is prescribed or if a change in prosthetic prescription occurs (e.g. from a body-powered to a myoelectric prosthesis).
- All people with upper limb amputations engaging in education and/or employment have access to specialist advice to assist with meaningful return to work or study.
S8. Upper limb amputation

The person who has experienced an upper limb amputation requires access to a specialist upper limb amputee rehabilitation service.

Quality measures

**System Measurements**
- There is a documented process for access and referral to local occupational therapy and prosthetic team.
- Service availability at specialist upper limb amputee clinic.
- There is a documented process for access and referral to specialist upper limb amputee clinics.

**Patient Measurements**
- Patient reported measures.
- Participation in activities of daily living.
- Functional upper limb assessments and outcome measures.
- Quality of life measurement scales.
P1. Care of the residual limb

Care of the residual limb and management of risk factors for further amputation are addressed.

Context

Management of the residual limb is vital to the ongoing health, vitality and activities of daily living for the person. To facilitate engagement in everyday activities, it is important to prevent contractures, wound breakdown, skin issues, and revisions or further amputation. Education specifically addressing these issues is provided as early as possible and reinforced throughout all phases of care.
Applying the standard in practice

- Discussion with the person about the likely appearance of the residual limb, where their limb will end, residual limb pain, phantom pain, phantom sensation, expected healing times and potential for prosthetic use occurs pre-operatively.

- Immediate post-surgical care includes education on wound healing and oedema management; prevention of contractures; and ongoing care of the residual limb.

- RRDs are utilised in transtibial amputations, where there are no clinical contraindications. *(see Practical Tools and Guides)*

- Care and hygiene of the residual limb and contracture prevention are emphasised in all phases of care.

- Education is provided regarding prosthetic use and fit, sock management and hygiene, weight management and fluid fluctuations.

- A plan for ongoing care is provided and includes provision of contact details (therapy, clinic and prosthetic) should any residual limb issues occur.
P1. Care of the residual limb

Care of the residual limb and management of risk factors for further amputation are addressed.

Quality measures

**System Measurements**

- Skin integrity measures.
- Re-amputation rate.
- Revision rate.

**Patient Measurements**

- Patient reported measures.
- Proportion of people provided with specific education regarding care and hygiene of the residual limb, prevention of contractures, skin care.
P2. Education across all stages of care

Education begins in the preoperative phase and continues across all phases of care.

Context

The person and their valued others receive appropriate education regarding the surgical procedure itself, the components of post-operative care, their expected rehabilitation outcomes and their ongoing care requirements including prevention and self-management strategies. A variety of formats are used including verbal, written and digital formats to accommodate the preferences of the person and their valued others.

The provision of information, coping skills training, and self-management training is provided during all of the phases of care. Provision of education is the responsibility of the person’s care team and is delivered by the most appropriate team member responsive to the person’s education requirements. Education is continuous and should be repeated and reinforced to meet the ever changing needs of the person. All team members are responsible for delivering education across the care journey.
P2. Education across all stages of care

Education begins in the preoperative phase and continues across all phases of care.

Applying the standard in practice

Education addressing the following topics is provided and is tailored to the individual, appropriate to their information needs:

**Impairment-based interventions**
- Residual limb management.
- Wound management.
- Oedema control.
- Rigid removable dressings.

**Environmental factors**
- Interdisciplinary team members and their role.
- Phases of rehabilitation care:
  - Pre-operative
  - Post-operative
  - Rehabilitation
  - Lifelong care.
- Peer support.
P2. Education across all stages of care

Education begins in the preoperative phase and continues across all phases of care.

Applying the standard in practice (cont’d)

Activity- and participation-based interventions

- Care of the residual and contralateral limb.
- Pain and sensation management.
- Counselling/coping skills.
- Chronic disease management/secondary prevention:
  - Diabetes management including podiatry management
  - Management of lifestyle risk factors such as smoking cessation, nutrition, diet and weight control, exercise maintenance.
- Prosthetic and non-prosthetic management.
- Falls prevention/management.
- Driving/vocation/leisure.
P2. Education across all stages of care

Education begins in the preoperative phase and continues across all phases of care.

Quality measures

**System Measurements**
- Documented process for the provision of educational resources.
- Educational resources are available in a variety of formats that reflect the demographic of the service population.
- Use of service-specific or generic education information such as education fact sheets, booklets and flyers.

**Patient Measurements**
- Pre- and post-education questionnaires.
- Patient experience of education survey.
- Documentation of education provided.
Context

Pain management is an important part of care for the person. Pain may occur before, during and/or after amputation. The person may experience pain for a number of reasons including the initial injury or illness, amputation surgery, phantom limb pain, residual limb pain, secondary musculoskeletal pain (e.g. low back pain, pain in non-affected limb) or chronic pain.

The assessment and monitoring of the person’s pain should commence pre-operatively and continue throughout rehabilitation and lifelong management phases. Knowledge of the potential causes of pain is needed to guide proper management. The pain treatment approach taken will vary depending on the cause and acuity of the pain and may include pharmacological and non-pharmacological interventions.
Applying the standard in practice

- During the pre-amputation consultation, the person is:
  - assessed for any pre-existing pain including type and acuity, and
  - educated on the possible types and management of pain post-amputation.

If any pre-existing pain is well controlled, the same pain management should continue post-amputation with adjustments made depending on new causes of pain.

- A formal pain management plan is developed in advance based on the pre-operative pain assessment.
- Referral is made to specialist pain team, as required.
- Clinicians are aware of possible reasons of pain including the initial injury or illness, amputation surgery, phantom limb pain, residual limb pain, secondary musculoskeletal pain or chronic pain.
- Acute post-operative pain is treated in accordance with established guidelines for post-operative treatment of pain.
Applying the standard in practice (cont’d)

• Any ongoing pain intervention is evaluated for its efficacy and adverse events.
• Pain management is monitored and addressed from an interdisciplinary perspective during all phases of care.
• Where specific treatable causes of pain are evident, appropriate treatments are applied based on the underlying aetiology.
• At each service contact throughout lifelong care, pain control is reviewed. Associated musculoskeletal pain may develop over time and it is assessed and treated appropriately. Ongoing review of pain medication needs to be conducted by medical physician and the pharmacist.
• Changes in a person’s life role, prosthetic use, or functional ability may impact on the person’s experience of pain. Access to a team experienced in management of amputation, and a pain medicine team is recommended.
P3. Pain

Pain is assessed, managed and monitored at all stages of care.

Quality measures

System Measurements

- Initial assessment or consultation forms that include items on pain assessment, education and management.
- Information booklets or written handouts include content on different types of pain and management strategies.
- Pain interventions offered are both pharmacological and non-pharmacological.

Patient Measurements

- Documented use of a validated pain assessment tool.
P4. Special consideration for specific populations

Special consideration is given to the needs of specific populations when managing the person with an amputation.

Context

Membership of the multidisciplinary team is expanded for persons with special needs, this includes:

- Aboriginal and Torres Strait Islander people/s
- Older persons
- Transition to adult services
- Persons engaged in highly physical activities
- Culturally and linguistically diverse populations
P4. Special consideration for specific populations

Special consideration is given to the needs of specific populations when managing the person with an amputation.

Applying the standard in practice

- The Aboriginal Liaison Worker and Aboriginal Chronic Care team are part of the multidisciplinary team for persons of Aboriginal or Torres Strait Islander background from the decision to amputate or earlier.
- Access to geriatric team expertise including geriatricians, dementia specialists and aged health clinical nurse consultants are available for people over the age of 65 years.
- The transition care coordinator is part of the multidisciplinary team for young people transitioning to adult services.
- An exercise physiologist is part of the multidisciplinary team for people engaged in highly physical activities and there is consideration for their leisure activities.
- There is access to culturally and linguistically diverse-appropriate resources for culturally and linguistically diverse populations.
P4. Special consideration for specific populations

Special consideration is given to the needs of specific populations when managing the person with an amputation.

Quality measures

System Measurements

- The service has documented linkages with specialist service providers including:
  - an Aboriginal liaison worker
  - an Aboriginal chronic care team
  - an aged care clinical nurse consultant
  - transition care coordinator(s).
- Evidence of referral to supporting services.

Patient Measurements

- Patient reported measures.
- All people identifying as Aboriginal or Torres Strait Islander are provided access to the Aboriginal Liaison Worker.
This self-assessment tool can be used by health services to evaluate their existing service provision and identify areas for improvement necessary to meet the expected standards of care in NSW as outlined in the Minimum Standards document.
The purpose of this guide is to recommend the use of a removable rigid dressing (RRD) in patients who have undergone a transtibial amputation. An RRD is a post-operative dressing used after a below knee amputation to protect and reduce oedema in the residual limb.


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