

# Lifetime

S U P P O R T

## Guidelines for treatment, care and support for amputees within the LSS living in the community

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## Introduction

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The purpose of these Guidelines is to provide an evidence based approach for provision of reasonable and necessary treatment, equipment, prosthetics, home modifications and attendant care for amputees accepted into the Lifetime Support Scheme living in the community.

In determining whether requests are 'necessary and reasonable' the Lifetime Support Authority will consider a number of factors, including the following:

- benefit to the participant;
- appropriateness of the service or request;
- appropriateness of the provider;
- cost effectiveness considerations; and
- relationship of the service or request to the injury sustained in the accident.

Within the LSA eligible amputations injuries are defined as amputation or the equivalent impairment, of the following types:

- A brachial plexus avulsion or rupture equivalent to an amputation; or
- Single amputation of the following types:
  - forequarter amputation or shoulder disarticulation; or
  - amputation of the lower limb through or above 65 per cent of the femur.
- Multiple amputations - there is more than one of the following amputations of the upper and/or lower limbs:
  - at or above 50 per cent of the tibia (lower limb); and/or
  - at or above the first metacarpophalangeal joint of the thumb and index finger of the same hand.

Therefore, where described upper limb amputees for the purpose of these guidelines are considered to be above elbow "full" upper limb amputees and lower limb above knee amputees with a short stump.

These guidelines will have only broad application to other, lesser levels of amputation (e.g. where there is more residual limb than indicated in the LSS Rules).

Multiple amputations are only be briefly considered as a separate category due to the multiple potential variations within this group which limit clear description of specific recommendations for this group.

## Background

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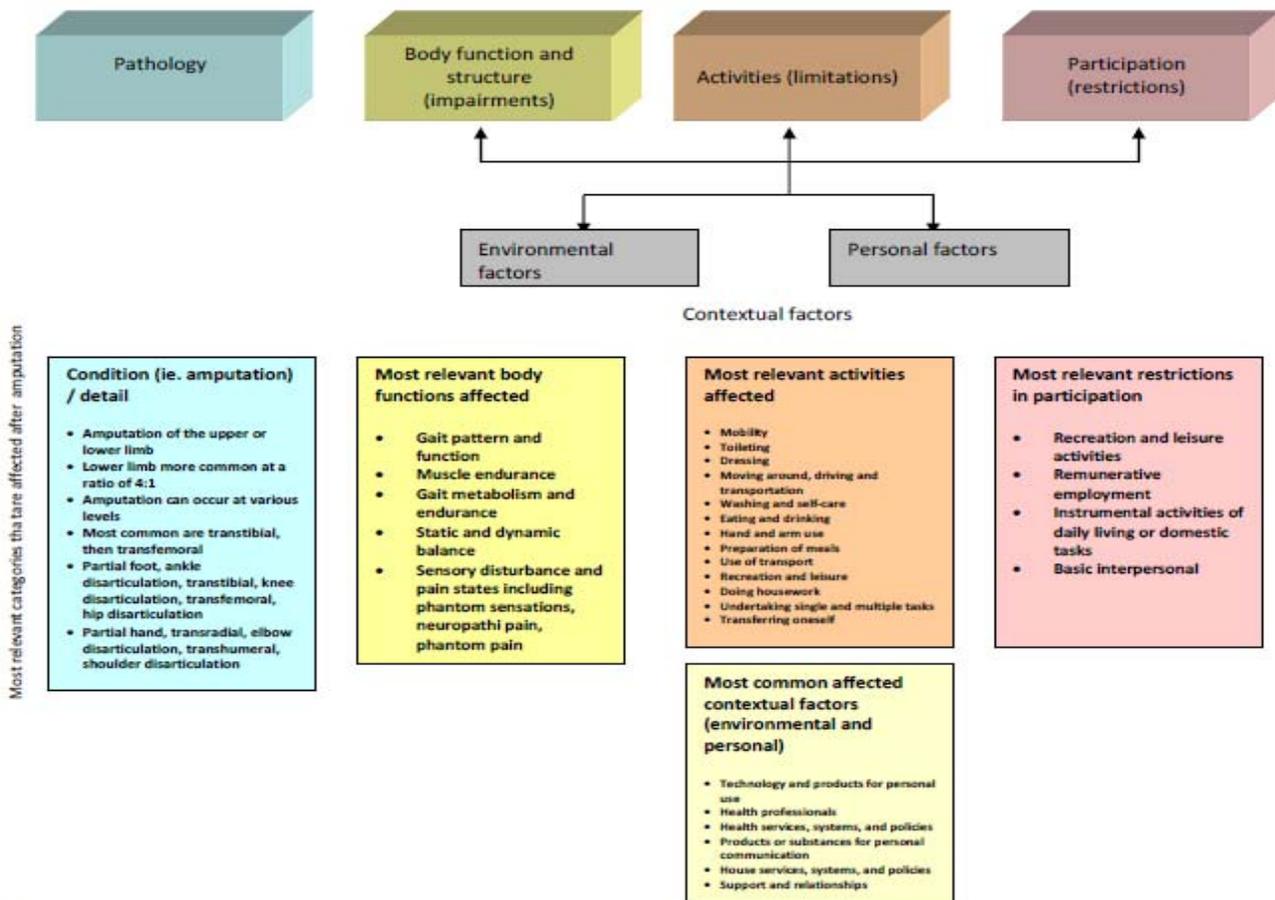
In Australia there currently exists a Model of Amputee Rehabilitation in South Australia for SA Health, Amputee Care Standards in NSW, and Amputee Services and Rehabilitation Model of Care through the Aged Care Network in WA.

However, these documents are specific to the health setting for which they were developed, describe state specific services and do not make detailed recommendations about what should be considered necessary and reasonable treatment, care or support within a community setting, nor do they provide extensive consideration of the ongoing needs of amputees through their lifetime.

These documents also primarily describe amputations as a result of vascular disease or diabetes mellitus where age, lifestyle and planning for the amputation may be more prevalent issues and influences on the experience of the amputee as compared to those experiencing a traumatic amputation as a result of a motor vehicle accident.

Therefore the **Guidelines for treatment, care and support for amputees within the LSS living in the community** are proposed to fill this gap in the literature and to guide the provision of treatment, equipment, prosthetics, home modifications and attendant care for upper limb, lower limb and multiple limb amputees.

The World Health Organisation's ICF Framework – amputee elements shows the impact of amputation (primarily) upon a person's activity participation<sup>1</sup>.



<sup>1</sup> Adapted from Statewide Rehabilitation Clinical Network (2011).

## Treatment

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Rehabilitation of individuals post amputation is critical to maximise their physical, psychological and social wellbeing thereby optimising their independence, function and life roles (Statewide Rehabilitation Clinical Network 2012). Rehabilitation and therapy interventions encourage people to look to the future and to develop their full potential as well as playing a vital role in motivation for participation in daily activities and providing hope for the future (Roberts 2008).

The improvement of an individual post amputation is impacted by age, physical and mental health, nutritional status, tissue perfusion, complications post amputation (e.g. poor wound healing or infection), the individual's motivation, level of amputation, presence of other medical conditions, smoking habits, suitability for prosthesis and the availability of rehabilitation programs (Statewide Rehabilitation Clinical Network 2012).

While inpatient rehabilitation is often emphasised for lower limb amputees due to a focus on mobility goals and prevention of falls, inpatient rehabilitation is often not provided for upper limb amputees, as they can readily learn one handed techniques to manage essential personal care tasks and thus, can be discharged home often within 1 -2 weeks post injury, depending on their wound healing and recovery. However, rehabilitation remains an essential facet for treatment of individuals with upper limb amputation to ensure they can maximise independence and optimal functioning of all personal and domestic activities of daily living, instrumental activities of daily living, transportation and achieve return to productive work roles where possible.

It is estimated that recovery post amputation occurs over a 12 to 18 month post-operative period including activity recovery, reintegration and prosthetic management and training (Berke 2004).

### **Phases of amputation rehabilitation and treatment required**

The pathways and phases for amputees are described variously in the literature however, for the purpose of these Guidelines the following is indicative of the stages involved:

1. Pre Operative stage where a decision is made to amputate and of the level of amputation including residual limb. It is anticipated that in traumatic motor vehicle accidents this phase may be very short due to the immediate urgency of emergency surgery post-accident.

2. Acute hospital phase including surgery, operative and post operative medical care until medically stable. This would include wound care management.
3. Rehabilitation phase including pre prosthetic and interim prosthetic phases. Rehabilitation aims to improve functional status with or without prosthesis and to successfully reintegrate in to home and community.
4. Advanced rehabilitation in community setting including accessing definitive prosthetic services and prosthetic training and rehabilitation.
5. Ongoing lifelong management where ongoing prosthetic review, services and rehabilitation may be required depending on changes throughout the participant's lifespan.

(Statewide Rehabilitation Clinical Network 2012, Berke 2004, Agency for Clinical Innovation 2008).

## Goals of Rehabilitation

“Whole person” goals of care for patients undergoing amputation have been described as follows:

- Musculoskeletal reconditioning and cardiopulmonary training.
- Contralateral limb preservation.
- Emotional care related to concepts of loss, mourning and the need for peer support and education.
- Minimisation of systemic complications.
- Social reintegration.
- Setting realistic patient expectations and functional outcome goals.

(Berke 2004)

It is noted that healing of a residual limb is a continuous process and thus a limb does not have a clear and decisive point of “being healed” (Berke 2004).

## Lower Limb Amputation Rehabilitation

Wong and Bourke (2007) have described that limited access to community based rehabilitation following lower limb amputation can result in increased length of stay in inpatient rehabilitation as patients may remain in inpatient facilities until all rehabilitation goals were met even if they were safe to go home earlier in a wheelchair. Thus access to community based rehabilitation and treatment, organised to commence in a timely manner post discharge is considered essential. Community based treatment and rehabilitation not only allows for early discharge but also enables the participant the opportunity to develop and practice mobility skills in a functional and “real” context,

such as their home and community, sooner (Wong & Bourke 2007) which may increase their rehabilitation outcomes.

It should be noted that patients may be discharged for wound healing with intended rehabilitation in the future (e.g. inpatient, day rehabilitation or outpatient rehabilitation) and therefore, suitable exercises including strengthening and endurance exercises should be implemented during this time (Statewide Rehabilitation Clinical Network 2012).

Access to structured centre based or community based rehabilitation, including review and reassessment as self progressive rehabilitation takes place, needs to be available for the remainder of the amputee's life (Statewide Rehabilitation Clinical Network 2012).

Functional training to maximise independence in everyday activities needs to be addressed in both a wheelchair and with a prosthesis (Statewide Rehabilitation Clinical Network 2012). Competent wheelchair skills are essential as even for those patients prescribed a prosthesis there are likely to be times when it is not possible to use a prosthesis including poor fitting, and injury to residual limb (Statewide Rehabilitation Clinical Network 2012).

## Pre-prosthetic intervention

Treatment and intervention may be required pre provision of prosthesis, such as:

- Identifying the needs/requirements for the prosthesis to achieve functional goals;
- Strategies, aids and equipment to manage daily activities irrespective of prosthetic outcome;
- Strategies, intervention and support to manage phantom limb pain; and
- Support in relation to body image, adjustment to body schema and preparation for how this may alter or change (positively or negatively) with provision of prosthesis or medical intervention.

## Post-prosthetic intervention

- Training to ensure maximal functional outcomes with the prosthesis. Prosthetic training both with prosthetist and with a suitably experienced health professional is an essential element of provision of a prosthesis in order to ensure maximal use in daily activities, including donning and doffing the prosthesis;

- Identification of tasks that can be performed with the prosthesis; and
- Identification of tasks that cannot safely be performed with the prosthesis and alternative methods, strategies, aids or devices to complete these tasks.

## The Multidisciplinary Treating Team

Multidisciplinary rehabilitation is recommended for people with amputations and should include:

- Compression wrapping techniques to decrease oedema (Berke 2004)
- Collaborative goal setting
- Liaison with medical and nursing services as required
- Ongoing management for prevention of contractures
- Controlling residual limb volume changes
- Pain management
- Residual limb activity including desensitisation, muscle contractions and endurance (Berke 2004).
- Independence with activities of daily living
- Musculoskeletal reconditioning (Berke 2004)
- Driving and transport including, for lower limb amputees, potential left foot accelerator use if the right leg is amputated, potentially hand clutch if left foot amputated and drives manual vehicle or potentially restrictions to driving automatic only if the left foot has been amputated. It should be noted that prosthesis with appropriate flexed knee joints can indicate potential to drive with a prosthesis. And for upper limb amputees, potential spinner knob and signal level extensions to enable one handed driving. All transportation would require Driver Trained Occupational Therapy assessment.
- Home modification needs identification
- Equipment usage and needs
- Support groups such as Limbs4Life. Peer support can be essential as an emotional outlet and for information, education and support (Berke 2004).
- Education of stump protection

In addition to the above for lower limb amputees this should include:

- Mobility with and without prosthesis. Mobility with the prosthesis should include training to increase body awareness and minimise excessive energy expenditure to maximise efficiency when mobilising with the prosthesis (Berke 2004).
- Community transfers such as car transfers, public toilets and confined spaces
- Falls education at home and in the community
- Wheelchair use

- Trunk stability and core strengthening of the pelvis, trunk and shoulders (Berke 2004)
- Sitting and standing postures (Berke 2004)

(Statewide Rehabilitation Clinical Network 2012)

## Occupational Therapy Role

Occupational Therapy may involve assessing, adapting and modifying home or other environments to facilitate participation (College of Occupational Therapists 2011). Occupational Therapists may address return to work including workplace assessment, task analysis, capacity and motivation building (College of Occupational Therapists 2011). Evidence suggests that return to work increases over time since amputation and thus there may be the need for long term vocational rehabilitation (College of Occupational Therapists 2011) and occupational therapy to facilitate an effective outcome in this domain.

In the initial post injury period Occupational Therapy services may be required as follows:

- Home visit prior to discharge, to identify equipment or home modifications unique to the home setting to ensure that where possible, the individual is discharged with appropriate aids to assist them to manage as independently as possible. This minimises frustration, facilitates independence and prevents dependence on others to assist them with daily tasks.
- Home visit within 1 week of discharge, or within 3 days of discharge if not provided prior to discharge, to ensure the person has all the recommended equipment and modifications. Also to identify issues and teach strategies for managing within home environment that may not have been addressed in the inpatient setting.
- 3 other home visits, within first 3 months, with reviews as required, to implement any further equipment or provide further problem solving and strategy development to focus on personal and domestic activities of daily living.
- Joint visit with prosthetist on at least one occasion to be part of identifying a suitable prosthesis to attain functional goals.
- Joint visit with prosthetist on at least one occasion, post prosthetic provision, to identify componentry, set up and configuration of the prosthesis to enable effective task orientated training.
- Home visit to ensure applicability within the individual's own context and environment as there are factors that influence performance specific to the setting and it can be difficult for the individual to generalise from therapy sessions to their own environment without support.

- Sessions to address performance of leisure and recreation activities, driving assessment, phantom limb pain interventions and prosthetic training depending on the individual needs of the participant.

Phantom limb pain intervention and prosthetic training can be completed in a clinic setting as long as there are sessions scheduled within the home environment or support insitu (e.g. telerehabilitation or attendant care support) to provide assistance with transfer of skills learnt in the clinic to the home environment. Individual treatment plans identifying goals, outcomes and sessions required to achieve these should be clearly articulated.

### **Upper limb amputees**

The functional goals of upper limb amputees are a key component of an occupational therapist's scope of practice. Occupational therapists are uniquely suited for upper limb prosthetic training due to their experience in problem solving and facilitating functional improvements. Prosthetic training includes gaining skills in basic grasp, release, stabilisation in smooth and spontaneous manner in a variety of positions and heights with integration of basic skills into daily activities (Roberts 2008). Participants should develop confidence with their prosthesis through completion of repetitive tasks and varied functional tasks (Roberts 2008).

Occupational Therapy role may include:

- Supporting changes in hand dominance (Roberts 2008)
- Safe lifting (Roberts 2008)
- Graded activity programs (Roberts 2008).
- Prosthetic training
- Management of phantom limb pain including graded motor imagery/mirror box training

### **Physiotherapy Role**

The physiotherapy role with amputees includes addressing the following:

- Residuum shape through bandaging/management
- Ensure optimal physical range of movement and strength.
- Protection and prevention of issues in unaffected body parts
- Management and support for phantom limb pain including graded motor imagery and/or de-sensitisation and other strategies in conjunction with Occupational Therapy

### **Upper limb amputees**

The physiotherapy role for upper limb amputees also includes the following:

- Muscle strength including core stability, conditioning and strength is essential to ensure adequate strength to support a prosthetic limb and to ensure appropriate muscle contraction for potential use of a myoelectric prosthesis.
- Postural stability, strengthening, flexibility and aerobic capacity in a physiotherapy program can minimise overuse injuries of the neck and back (Roberts 2008).
- Physiotherapy treatment may also be required to address neck and back discomfort and pain resulting from prosthetic use.

#### *Intensity of program*

Physiotherapy input addressing residual limb function and muscle strengthening (as described above) should be provided by a therapist skilled and experienced in working with amputees. The service would be expected to be provided up to 2 times per week for 12 weeks with progression towards independent exercises or self-managed gymnasium programme thereafter, with monitoring of function and regular reviews for 6 – 12 months depending on provision of the prosthesis. It should be noted that this will vary, as appropriate, for the individual to achieve realistic short/medium term goals.

#### *Post-prosthetic intervention*

Physiotherapy involvement post prosthetic provision is important to monitor impact of prosthesis on shoulder and neck. Musculoskeletal Physiotherapy to address shoulder, neck and trunk pain may be required as indicated and does not need to be provided by a practitioner with amputee expertise. An individual treatment plan would be developed with a focus on self-management to support ongoing symptom management.

### **Lower limb amputees**

The primary provider of therapy services with a lower limb amputee is likely to be a physiotherapist working in conjunction with an occupational therapist. The physiotherapy role for lower limb amputees also includes the following:

- Strength, range of movement, cardiovascular and balance exercise in order to maximise efficiency of gait, improve functional capacity and enhance prosthetic outcome (VA/DoD 2008).

- Mobility, balance and gait training (with and without prosthesis) including building endurance for accessing the community and management of steps, stairs, uneven surfaces and ramps/inclines (VA/DoD 2008).
- Weight bearing, standing balance/tolerance and weight shifts (VA/DoD 2008)
- Bed mobility, sitting, standing, balance and transfer training
- Contracture prevention through stretching, splinting and positioning
- Exercises for hip extensors, flexors and abductors and ankle plantar flexors
- Desensitisation of the residual limb as well as limb volume management
- Wheelchair and mobility aid/training
- Falls prevention
- Functional training tasks including but not limited to
  - Getting on and off the floor
  - Getting in and out a car
  - Managing stairs, kerbs, ramps and slopes
  - Walking in a crowded environment
  - Carrying objects while walking
  - Walking over uneven ground including outdoor and community mobility
  - Changing speed and direction
  - Picking up objects from the floor
  - Reaching, bending and lifting at floor or below waist
  - Use of public transport, escalators and community settings

(NSWPAR & BACPAR 2008)

Functional training should be used both with and without the prosthesis to ensure the participant can manage irrespective of the aids used.

## **Psychology Role**

Counselling support and psychology intervention may be required to address grief relating to the loss of limb (Statewide Rehabilitation Clinical Network) as well as body image issues. Clinical counselling and psychological support may begin in the acute phase and continue in required as part of lifelong management (Agency for Clinical Innovation 2008).

All individuals with an amputation should be offered psychology input prior to and upon discharge and a treatment plan developed depending on their individual needs and circumstances.

## Prosthetist Role

The primary roles of the prosthetist is to develop and supply the prosthesis. Rehabilitation services should include prompt access to prosthetists to monitor patient fit and functioning on an ongoing basis, and coordinate the manufacture, fitting, adjustment and repair of prosthesis (Statewide Rehabilitation Clinical Network 2012). Refer to Prosthetics section for details.

It is essential that the prosthetist, Occupational Therapist (for upper limb amputees) and physiotherapist work collaboratively in:

- the selection of a suitable prosthesis for functional goals,
- preparing the participant for using a prosthesis and
- the training, use and management of a prosthesis upon provision.

It is recommended that joint visits are completed by the therapists with the prosthetist to ensure that all goals for prosthetic use are considered and incorporated into prosthetic provision where possible, or in to the individual treatment program if not able to be achieved through provision of the prosthetic, and post prosthetic provision to ensure an effective outcome, particularly for training purposes.

## Medical Treatment

Medical and surgical involvement can occur post amputation if there are complications such as poor wound healing, infection or if revision surgery is required to address these issues or for cosmetic reasons.

## Osseointegration

Osseointegration is a growing treatment area and it is understood that there are two clinics currently in Australia completing osseointegration and neither of these is located in South Australia, although patients are accepted from interstate for this technique. These clinics offer differing prosthetic protocols including differing time lapses between the phases involved. There are considerations, including risk of infection, use of a stoma and body image issues, that may impact an effective prosthetic outcome from this surgery. For lower limb amputees, recovery and rehabilitation can be prolonged over a period of time to ensure safe and security of the metal implant in the bone during weight bearing and building tolerance for weight bearing.

There are indications that osseointegration can result in improved prosthetic outcome due to improved fit and suspension, which means less need to change or adjust the

socket. As such can reduce the extent of prosthetist involvement in the future; however, to what extent is not clear.

### *Upper limb amputees*

One of the primary issues for upper limb amputees, particularly whole arm amputees or equivalent, is that of suspending the prosthesis from the body. As a result there are a number of medical techniques that are being further explored and used to address these issues including:

- Osseointegration; direct anchorage of the prosthesis to the skeleton using metal implants inserted in to the bone;
- Targetted muscle reinnervation; nerve transfers using residual nerves on to alternative muscles to obtain strong electonyographic signals which can be detected by electrodes to operate a prosthesis; and
- Bone lengthening to increase residual limb length with benefits for prosthetic suspension and control.

(Roberts 2008)

## Equipment

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Equipment needs to be available and easily accessible at all amputee rehabilitation services and may include the following items (which may be provided while an inpatient or for discharge):

- Bandages for wrapping the stump
- Residual limb socks for protection of the stump
- Shrinkers or compressive garments designed to aid shaping of the stump
- Rigid Removable Dressings (RRDs)
- Self care or activities of daily living equipment

(Statewide Rehabilitation Clinical Network 2012)

Rigid Removable Dressings provide optimal control of swelling and protection to the stump during the healing process and are considered best practice for stump management (Department of Health WA 2008, Statewide Rehabilitation Clinical Network 2012). It has previously been identified that these are not always supplied in a consistent method within the public hospital sector however, that it is a priority to be addressed.

Bandages, residual limb socks, compressive garments and RRDs are part of appropriate inpatient management of the amputee and would be expected to be provided and supplied within an inpatient setting.

## Upper Limb Amputees

Reasonable activities of daily living equipment that may be required, following an individual assessment to determine need, includes:

- Adapted cutlery including, but not limited to,
  - Rocker knife for cutting up food
  - Splade or spork
- Plate guard to clip to dinner plates and provide assistance in pushing food up on to the fork when eating one handed.
- Non slip matting for stabilising plates
- Hands free automatic or fillable soap dispensers to allow soap to drop into the one hand where person cannot press pump pack soap into the hand.
- Suction nail brush and suction nail cutting kit for one handed management of nails.
- Elastic shoe laces or “no bows” so the shoes can be done up once and the participant doesn’t need to manage shoelaces one handed.
- Alternate fasteners for clothing e.g. Velcro that can be used one handed.
- Sock aid to facilitate putting on socks one handed.
- Button hook for doing up buttons one handed.
- Spike board and bread board or kitchen workstation which has raised edges to butter bread one handed, spike to hold vegetables and clamp to hold a knife to enable one handed chopping
- Food processor or V-slicer.
- Wall mounted soap dispenser that can be filled with shampoo, conditioner and shower gel. This would also facilitate one handed use as pressing the lever would supply the liquid into the hand.
- Wall mounted shower sponge to enable washing of the contralateral (unaffected limb).
- Automatic wall mounted toothpaste dispenser to enable one handed use with the user pressing the tooth brush into the device which deposits toothpaste onto the brush.
- Suction cup bottle brush for stabilising the brush to wash dishes.
- Trolley for transporting shopping to increase efficiency with carrying bags or items one handed and to decrease lifting, carrying and transportation of items around the home.

- Spinner knob steering aid and indicator adaptations to facilitate effective one handed driving **pending Driver Trained Occupational Therapist assessment and recommendations, and medical clearance.**
- Voice activated software to enable ease of computer use compared to typing one handed.

It should be noted that this list is not extensive and further equipment items may be required depending on individual need and preferences. This could include consideration of innovative solutions to daily activities such as sack truck for lifting/transporting/carrying, self-propelled or ride on lawn mowers, or foot operated clamp for work benches.

### *Factors to consider in the provision of equipment*

One of the challenges when working with upper limb amputees relates to the participant learning to complete daily activities with one hand i.e. becoming “one handed”. There are a range of equipment and “one handed” techniques that can facilitate independence with one hand and can support a safe and effective discharge home (as described previously). It is accepted that early prosthetic provision can limit the extent of one handedness and attain better prosthetic outcome. Generally, unless wound healing, stump shape or other co-morbidities are present, prosthetic use is usually considered to be one of the key goals in order to attain maximal function, retain bilateral movements and facilitate resumption of pre injury activities and roles. Thus any equipment provided to accommodate one handed use needs to be considered in light of its longevity of use depending on prosthetic outcomes. Factors to consider include:

- Customised equipment and cost; is the equipment item likely to be used in the long term once the client has a prosthesis? Is there a standard, low cost item that could be used in the interim? What is the expected wait time for provision of the prosthesis?
- Does the item of equipment have a significant effect on function and independence in the short term that outweighs the potential non-use in the future?
- What is the anticipated frequency of use of the prosthesis (including wearing tolerance)? What is the percentage of day for which the prosthesis is worn? Would the item of equipment still be used in these situations/circumstances?
- How the person will function and complete daily activities when their prosthesis is not available (e.g. in case of skin breakdown or prosthesis repair)?
- Handedness and amputation of dominant and non dominant hand is also a consideration as loss of the dominant hand may have a poorer outcome on function

and thus additional equipment may be required to support the non dominant hand now being used as the primary upper limb.

It is noted that a prosthesis is not necessarily useful for all daily activities and clinical experience indicates that some activities can be completed more easily, quickly, effectively and independently without a prosthesis. Therefore it can be useful to provide the following:

- Break down of daily tasks and how they will be managed with the prosthesis and how they will be managed without the prosthesis and/or
- Tasks for which the prosthesis should be used and tasks for which alternative techniques or equipment should be utilised.

Phantom limb pain may be considered an issue in its own right and may require specific therapeutic modalities and equipment for proactive treatment and self management including, but not limited to:

- Mirror box (Roberts 2008);
- Online access to graded motor imagery resources and/or applications for use on portable electronic devices; and
- Resources such flash cards, Explain Pain book and Explain Pain Handbook.

Educational materials relevant to upper limb amputees may include:

- Book: One handed in a Two Handed World which described a range of alternative techniques for completion of daily activities one handed.
- Amp it Up! online magazine
- Link Disability magazine

## Lower Limb Amputees

In addition lower limb amputees may require the following:

- Residual limb supports (e.g. stump board) (Statewide Rehabilitation Clinical Network 2012, College of Occupational Therapists 2011)
- Mobility aids
- Wheelchair
- Pressure cushion for support of residual stump

(Statewide Rehabilitation Clinical Network 2012)

### *Factors to consider in the provision of equipment*

#### *Use of a wheelchair*

It should be noted that use of a wheelchair as “back up” mobility when a prosthesis is not available is considered to be standard practice and in some instances may be preferable to using a prosthesis in some situations due to comfort, function and energy factors (College of Occupational Therapists 2011, VA/DoD 2008). A wheelchair may increase and enhance function e.g. when a participant may have been using the prosthesis during the day but returns home in the evening and “can’t wait” to get the prosthesis off, they may find accessing the home in the wheelchair is convenient and requires less physical demands compared to using crutches.

#### *Use of mobility aids*

Mobility aids such as crutches (elbow or forearm), 2 wheeled walkers or 4 wheeled walkers may be considered to support mobility with a prosthesis or mobility aids when a prosthesis is not being used, either in the short term or potentially, in the longer term when prosthesis is unavailable for use, or when a prosthesis have not been successful. It should be noted that in some instances, mobility aids such as crutches, may be used to overcome significant environmental barriers e.g. steps. Again this could either be in the short term while awaiting home modifications, or if home modifications are not possible or declined by the participant. However, it should be noted that the preferred alternative mobility device when a prosthesis is not used, is recommended to be a wheelchair (College of Occupational Therapists 2011). This is due to complications, particularly shoulder pain/discomfort and overuse, from long term use of crutches. Further research is needed to determine the risk that “hopping” (even with support and use of mobility aids) poses to the contralateral foot and a lack of robust evidence for the effectiveness (or otherwise) of hopping means that the risk involved in this style of mobility cannot be quantified and therefore this method of mobility should be recommended with caution (College of Occupational Therapists 2011).

## Prosthetics

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The LSS can pay for reasonable costs of a prosthesis and associated equipment (e.g. sleeves, liners, gloves) where it promotes functional independence, self-management or cosmetic improvement.

There is limited literature that extensively describes the benefits of prosthetic provision however, literature reviewed implies that rehabilitation for amputees always considers prosthetic use as a primary goal and non-use of prosthesis is implied as an undesirable outcome, for which reasoning needs to be clearly articulated and described. It is assumed that this is because a prosthesis provides an immediate substitute for the amputated limb and thus is considered an essential requirement to regain the highest level of bilateral functioning possible. Research does indicate support for prosthesis for upper limb amputees to assist with swelling and provide relief from phantom limb pain.

It should also be noted that a successful prosthetic outcome is reliant upon the following features of a prosthesis:

- Comfort and fit which enables sufficient wearing tolerance for the tasks the participant is intending to use the prosthesis for;
- Easy to get on and off;
- Lightweight;
- Reliable and durable, not requiring constant repair, replacement parts or adjustments;
- Aesthetically and cosmetically pleasing to potentially enhance body image; and
- Functions well, consistently and effectively with a reasonable but not excessive use of effort.

Other factors that influence an effective outcome of the prosthesis include:

- Participant's acceptance, willingness and commitment to use it for meaningful activities;
- Functionality of the prosthesis to match the tasks that the person wishes to complete.

The provision of interim prostheses immediately post amputation is expected to be the responsibility of the hospital or rehabilitation service. It is understood that early prosthetic use is closely associated with improved functional outcomes and as such, interim prosthetics should be considered and quoted for by the prosthetics service as soon as practicable.

## Lower Limb Prosthesis

A lower limb prosthetic system for a transfemur amputation or higher includes hip joint (if required), socket that encases the residual limb, harness/suspension system, knee

joint, foot and pylon to connect the knee to the foot. The knee system is essential for achieving effective mobility and there are 2 primary knee systems:

- Mechanical system which involves a hinge for the knee controlled by hydraulics or a locking mechanism
- Microprocessor systems which consist of sensors, the processor, software, resistance system and battery. The microprocessor controls the fluid hydraulically or pneumatically and adjusts resistance depending on speed, steps, ramps and uneven surfaces. Microprocessor systems can be used by most amputees irrespective of the level of amputation.

There are multiple systems and suppliers for knee and foot components who can provide detailed comparison charts to assist with matching the prosthesis for the participant's functional abilities. Considerations for the provision of knee and foot components include need to be used for the following tasks:

- Managing uneven surfaces
- Walking backwards
- Managing obstacles
- Going up and down stairs
- Going up and down hills, slopes and ramps
- Ability to lock and have variable positions
- Used for and able to achieve appropriate positions for functional tasks such as sitting, driving, biking, golf or other recreational activities.
- Adjustability to stance, cadence, variability of walking speed
- Use indoors or outdoors
- Durability and frequency of use

Use of liners and sleeves provide a protective cover and flexible cushioning that reduces movement and chafing between the skin and socket of a prosthesis and include silicone, polyurethane and copolymer options. Liners should be selected based on their suitability for the prosthesis used and the participant's activity level.

## Recommendations for Prosthesis

The LSS can pay for reasonable costs of a prosthesis taking into account whether it promotes functional independence, self-management and/or cosmetic improvement.

## Interim Prosthesis

The provision of interim prostheses immediately post amputation is expected to be the responsibility of the hospital or rehabilitation service. It is understood that early prosthetic use is closely associated with improved functional outcomes and as such, interim prosthetics should be considered and quoted for by the prosthetics service as soon as practicable.

The Lifetime Support Authority requires that quotations for interim prosthesis are to be accompanied by medical practitioner or suitably qualified therapist recommendations regarding anticipated functional use, duration of suitability of the interim prosthesis and the timeframe for assessment, construction and provision of the definitive prosthesis. Quotation for provision of each definitive prosthesis, attachments and recreational limbs will also require medical practitioner or suitably qualified therapist recommendations regarding functional use and outcomes to ensure best prosthetic match to the participant's needs and prevent potential abandonment of the device.

### *Upper Limb Amputees*

With upper limb prosthesis, particular emphasis should be placed on functional outcomes with and without a prosthesis (Agency for Clinical Innovation 2008).

### *Lower Limb Amputees*

Interim prosthesis are ideally fitted within 3 weeks of transfer to rehabilitation as they enable stabilisation of oedema, primary healing of the wound and minimise scarring (Department of Health Western Australia 2008). It is noted that healing of a residual limb is a continuous process and thus a limb does not have a clear and decisive point of "being healed" and the presence of a wound or sutures does not preclude weight bearing using a prosthesis (Berke 2004).

It is noted that through the South Australian Artificial Limbs Scheme, the average number of prosthesis is approximately 1.5 per client. However, it should be noted that this is a publicly funded, rationed scheme and thus may not be indicative of the needs of individuals for multiple prosthesis for different features, fitting and functionality. It is realistic and reasonable that lower limb amputees who use a prosthesis as their primary mobility device, would have at least 2 prosthesis particularly in the event that one may need repair. Ideally these would serve different purposes and functions e.g. one may be a water leg, an interim "old" prosthesis or "work" prosthesis.

## Definitive Prosthesis

A definitive prosthesis can be provided within 12 to 18 months post amputation however, is typically affected by fluctuations in limb volume which affects the comfort and fit of a prosthesis (Berke 2004). Limb stability is often achieved by 6 months of continuous prosthetic use and once the limb volume has stabilised to a point where socket fit is consistent for 2 – 3 weeks then this may indicate appropriate timing for a definitive prosthesis (Berke 2004).

Quotation for provision of each definitive prosthesis, attachments and recreational limbs will also require medical practitioner or suitably qualified therapist recommendations regarding functional use and outcomes to ensure best prosthetic match to the participant's needs and prevent potential abandonment of the device. Recommendations for prosthesis from medical practitioners and therapists should also detail required training and rehabilitation services following provision.

## Prosthetic training

Prosthetic training both with prosthetist and with a suitably experienced health professional is considered to be an essential element of provision of the prosthesis in order to ensure maximal use in daily activities including donning and doffing the prosthesis. Prosthetic training with the prosthetist is expected to be included in the quotation for provision of the device. It is understood that there are training protocols released by some prosthetic manufacturers and quotation for delivering said training will be sourced from a suitably experienced health professional and should be included in their recommendation for provision of the prosthesis.

The prosthesis should be reviewed by the prosthetist and health professional at least once in the first year of prosthetic use in order to address stability, ease of movement, energy efficiency and appearance and, for lower limb amputees, gait, to ascertain successful outcomes and problem solve any issues identified (VA/DoD 2008).

## Lower Limb Amputees

Prosthetic rehabilitation should aim to establish an energy efficient gait based on normal physiological walking patterns, the level of amputation and medical and social history (NSWPAR & BACPAR 2008). Prosthetic gait training should incorporate aspects related to the participant's home, work and/or recreational environments (VA/DoD 2008).

## Repairs, maintenance and servicing

Prosthetic user's requirements, physical functioning and stump shape may alter in time which may impact the comfort, fit and effectiveness of the existing prosthesis. Similarly prostheses may require repair, servicing or maintenance completed including new batteries, or adjustment for comfort and fit. It should also be noted that a prosthetic user is likely to require a new prosthesis every 3 to 5 years. A participant's needs of a prosthesis may change and new technology may be released and thus they may require a new attachment, fitting or new prosthesis to attain an improved functional outcome.

LSS can pay for the following:

- Maintenance of a prosthesis for its serviceable life;
- Modification or replacement of a prosthesis that no longer fits or no longer can be serviced, a change of prosthesis prescription is required;
- Repair, modification or replacement of a prosthesis outside the manufacturer's warranty.

## Replacement

It should also be noted that a prosthetic user is likely to require a new prosthesis every 3 to 5 years. Technology is continually growing and evolving in the realm of prosthetics and replacement prosthesis for "updated" models should not be expected unless improvements in function and performance are clinically indicated through use of a newer prosthesis. Considerations for prosthetics and prescription of prosthesis including changes for a prescription need to consider and make reference to activities completed at home, community, recreation and occupational activity level, impact level and body weight (Statewide Rehabilitation Clinical Network 2012).

## Specific considerations for prosthetic decision making

The LSS will consider the following factors, in addition to these guidelines, when making funding decisions about prosthesis

- Changes to the residual limb size and shape;
- Normal wear and tear;
- Activity level of the participant and types of activities the participant used to perform or would like to be able to perform;

- Any anticipated changes in the client's level of function and range of activities performed while using the prosthesis such as home, work duties or sports participation;
- Componentry costs and whether components can be re-used in replacement prosthesis and comply with relevant medical/therapeutic goods regulations;
- Inclusions of manufacturer and extended warranty, servicing and repairs;
- Durability and suitability for task performance;
- Aesthetic considerations including anthropomorphics, aesthetic limbs, covers and, for upper limb amputees, gloves.

## Upper Limb Amputees

It is noted that for LSS participants prosthetic use may be challenging due to the nature of the whole arm amputation which may require shoulder componentry along with elbow and hand componentry. Suspension of the prosthesis and residual muscles available for operation may be significant challenges to successful outcomes requiring high end prosthesis and novel solutions including myoelectrics, robotics and other emerging strategies.

## Specialised, higher-end prosthesis and novel, innovative and emerging technology

LSS can provide specialised, higher end prosthesis and prosthetic componentry when supported by objective clinical evidence that the prescription will result in a demonstrated improved functional outcome for the client. Where possible a trial of this prosthesis or prosthetic attachments would be recommended, and the outcome measures indicated below used, to indicate benefits and provide rationale and recommendations for ongoing use.

The LSS supports the development of novel, innovative and emerging technologies and values a partnership approach in identifying and implementing new and developing options in prosthesis and technology solutions for participants. If emerging technology is indicated as potentially suitable then consideration will be given for its use based on clinical evidence and rationale.

## Attachments

The LSS will provide up to 3 task specific attachments for an upper limb prosthesis with clinical evidence and rationale supporting their use by the prosthetist and occupational

therapist. This would only be upon provision of the definitive prosthesis with demonstration that it cannot safely effectively be used to complete specific functional activities and indication of how the attachments will facilitate completion of these tasks. This might include a “work arm”, gripper or tool attachments.

### **Water limbs, sporting and recreational activities**

The LSS will provide for lower limb amputees predominantly a water limb upon clinical evidence and recommendations of the physiotherapist or occupational therapist in the following instances:

- If participation in water activities is recommended/required e.g. hydrotherapy and/or
- If the participant demonstrates willingness and/or capacity to commit to continued participation in water activities and/or
- If required for functional reasons (e.g. in some instances a wet leg is required to access the bathroom and removed then for showering)

The LSS will provide an entry level sporting or recreational prosthesis for one sporting/recreational activity where the client can demonstrate a willingness and/or capacity to commit to continued participation or for more than one form of sporting activity where the participant can demonstrate a pre-accident commitment to more than one sporting or recreational activity.

### **Working activities**

It should be noted that one off custom appliances for work related activities should be available to the participant (Agency for Clinical Innovation 2008).

## **Measuring prosthetic Outcomes**

### **Upper Limb amputees**

The following tools are recommended to be used to measure upper limb prosthetic outcomes

- Disabilities of Arm, Shoulder and Hand (DASH or Quick DASH)
- Trinity Amputation and Prosthesis Experience Scales (TAPES)

The TAPES measures psychological adjustment, activity restrictions, prosthesis satisfaction, pain and other medical issues (College of Occupational Therapists 2011).

## Lower Limb Amputees

The following tools are recommended to be used to measure lower limb prosthetic outcomes:

- Locomotor Capabilities Index in Amputees
  - This is a self administered scale designed for people with lower limb amputation which measures perceived independence using the prosthesis to complete various mobility activities.
- Timed Get Up and Go Test
  - This is a measure of mobility which can be used as an outcome measure throughout the rehabilitation phase.
- K Classification
  - These are descriptive functional levels from the American Orthotic and Prosthetic Association used by manufacturers in classifying components
- SATPRO (Satisfaction with Prosthesis)
  - This is a self measure of satisfaction of lower limb amputees with their prosthesis.

(Agency for Clinical Innovation 2008)

- Trinity Amputation and Prosthesis Experience Scales
  - The TAPES measures psychological adjustment, activity restrictions, prosthesis satisfaction, pain and other medical issues (College of Occupational Therapists 2011).

## Home Modifications

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### Upper Limb amputees

There are minimal home modifications expected for upper limb amputations however, the following may be considered:

- Lever taps depending on the individual's capacity to independently and with one hand turn taps on and off in their home. A prosthetic limb does not have the capacity to complete this movement and standard twist grip taps may be difficult for the participant to manage with one hand.
- Wall mounted bath sponge to enable effective washing of the contralateral (unaffected upper limb).
- Wall mounted cannisters for shampoo, conditioner and body wash to enable effective one hand use as the liquid can be pulled directly in to the hand.

- Dishwasher, if they do not already have one, to enable effective and efficient washing of dishes. A prosthesis cannot be used in water effectively and thus hand washing dishes with one hand can be time consuming and frustrating particularly if the non dominant hand is the remaining limb. While equipment can support one handed dish washing e.g. suction cup sponge so dishes can be pushed up against the sponge to be washed, this can remain a time consuming and difficult task for upper limb amputees and provision of a dishwasher can reduce need for attendant care support.

## Lower Limb Amputees

It has been identified that early referral for home assessment and implementation of home modifications, equipment and care is essential to ensure timely discharge (Statewide Rehabilitation Clinical Network 2012). An accessible environment is also considered the key to promoting independence at home and work (College of Occupational Therapists 2011).

There is evidence that suggests that modifying the home to be wheelchair accessible increases participation in activities (College of Occupational Therapists 2011) irrespective as to whether or not a client is a wheelchair user full time or part time. It is acknowledged that prosthetic use can overcome obstacles that can be problematic for wheelchair access such as flights of steps. When considering home modifications, there needs to be a balance between ensuring access for a wheelchair in case the prosthesis is not able to be used and between ensuring the home is accessible with the device that will be used most often. For example, a house with multiple steps at each entrance way is essentially “inaccessible” in a wheelchair but is potentially accessible to a participant using a prosthesis or using crutches. If the participant is a full time wheelchair user, it may be reasonable to consider modifying more than one access point if clinically indicated for participating in functional tasks. However, if the participant is primarily going to use the prosthesis and can manage steps with the prosthesis, then wheelchair access modifications may only be provided or required at one entrance. It should be noted that many amputees find it difficult to walk on sloped or ramped surfaces, more so than managing steps (depending on the specific prosthesis used), and thus consideration also needs to be given to which access point will be used most often with which device.

Similarly, Collin et al (1992 cited in College of Occupational Therapists 2011) described that partial walkers had lower kitchen and domestic activity scores due to a lack of environmental modifications for wheelchair use. However, it should be noted that

lowering the height of kitchen benchtops to ensure access from a wheelchair, may negatively impact other members of the household who may end up bending over the surfaces. Similarly, if or when the participant stands to work in the kitchen using their prosthesis they may be hunched over surfaces. Therefore any modifications need to consider the percentage of day/time use of a prosthesis and for what activities within the home environment.

However, as a guide the following home modifications are considered to be reasonable and necessary for participants with lower limb amputation:

- Bathroom modifications are often essential as in this environment the participant cannot use their prosthesis throughout the personal care routine. Modifications may include level access to the shower alcove to avoid “hopping” over a step to enter and exit the shower alcove and modifications to the alcove to accommodate a shower chair and access to taps and water from a seated position (e.g. use of hand held shower hose). If long term residency is indicated and positioning the shower chair in the alcove was problematic, then a drop down shower seat may be of benefit as this is fitted to the wall and can flip up out of the way when the shower is being used by other members of the house hold.
- If the participant wants to complete any aspect of showering in standing (e.g cleaning perianal area) then a grab rail would be indicated.
- Modifications to step access with wheelchair accessible ramps or level access. Slope of the ramp should be considered depending on prosthetic use vs wheelchair use at the specific entry point.
- If the participant is a primary prosthetic user, then modifications to step access may incorporate bannister railing or grab rails to ensure external stability and support.
- Minor kitchen modifications where indicated e.g. lowering a benchtop to be wheelchair accessible will be considered. Extensive kitchen modifications would require case by case assessment and review.

Need for home modifications will be reviewed if prosthetic use is abandoned entirely.

## Attendant Care

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### Upper Limb amputees

It is anticipated that upon discharge from rehabilitation a participant with upper limb amputation will, as a minimum, be independent with personal care activities using one hand. In the absence of co-morbidities or cognitive impairment, it is therefore not

indicated that the participant with an upper limb amputation would require personal care assistance.

It is anticipated that community based rehabilitation would work towards independence with domestic activities such as meal preparation and cleaning. However, in the interim the participant may require 3 -4 hours per week of domestic assistance to manage laundry and cleaning activities. This is estimated to be required over a 6 month period with review of this service every 2 months to facilitate a graded increase in completion of domestic tasks and therefore graded reduction in services during this time.

It is anticipated that a participant living on their own may require up to 2 hours per week domestic assistance due to ongoing difficulties managing cleaning activities one handed if prosthetic use has not been successful. It should be noted that a prosthesis may be of limited assistance with these tasks due to the position needed to effectively position the hand to operate devices such as a mop and vacuum. Making the bed and changing the sheets can also be problematic. However, it should be noted that there are techniques and equipment that may assist a person to manage these types of tasks and therapy intervention should be directed towards independence wherever possible.

## Lower Limb Amputee

It is anticipated that upon discharge from rehabilitation a participant with lower limb amputation will, as a minimum, be independent with personal care activities provided appropriate home modifications, particularly bathroom modifications, have been completed. In the absence of co-morbidities or cognitive impairment, it is therefore not indicated that the participant with a lower limb amputation would require personal care assistance with showering, dressing or grooming in the long term.

Rehabilitation would work towards independence with domestic and community activities, primarily mobility. However, successful independence with these activities may be impacted by the extent to which mobility aids, in particular, wheelchair use is required. Mobility aids, excluding prosthesis, typically require the participant to support part of his body weight using his upper limb through the aid. This therefore restricts both upper limb use and mobility for completion of domestic activities such as cleaning and shopping. Meal preparation independence is primarily impacted upon the environment such as accessibility in the wheelchair vs standing tolerance for preparation. However, this should ultimately be able to be completed independently.

It is considered reasonable upon discharge to provide up to 5 hours per week of domestic assistance to manage laundry and cleaning activities. Duration of this service is dependent on timeliness and effective outcome of provision of prosthesis and effectiveness of alternative mobility strategies. A review of this service every 2 months to facilitate a graded increase in completion of domestic tasks is recommending during this time.

It is considered reasonable upon discharge to provide up to 2 hours per week of assistance with community activities such as shopping although it is expected, where possible, that this is completed *with* the participant rather than for the participant.

It is considered reasonable upon discharge to provide up to 2 hours per month of assistance with gardening activities such as mowing lawns and pruning, depending on pre-injury roles and expectations and size of block/garden to maintain.

Upon provision of the prosthesis, these hours should be reviewed and ongoing provision is dependent on prosthetic outcome, duration/wearing tolerance, frequency of use of prosthesis, alternative mobility strategies, return to work and other tolerance factors.

It would be expected that the maximum ongoing provision of attendant care hours for domestic, community and gardening activities would not exceed that upon discharge, unless co-morbidities, cognitive impairment or other factors are present.

## Considerations for Multiple Amputations

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There is a paucity of evidence and information for considerations for multiple amputees in relation to their treatment, equipment, prosthetic and attendance care needs.

It is anticipated and expected the existing guidelines would cover the needs and considerations required for the individual amputated limbs. However, it should be noted that while the nature of multiple amputations can be variable e.g. bilateral lower limbs, upper and lower limb involvement, the outcome is likely to be less independent functioning compared to a single amputation. For example, a bilateral lower limb amputee is likely to have a poorer prosthetic mobility outcome than a unilateral lower limb amputee and may therefore be a more consistent wheelchair user. An amputee with upper and lower limb amputations may have increased difficulty operating a wheelchair and may also have increased difficulty donning and doffing a prosthesis

due to the upper limb involvement. Therefore the functional implications are likely to be more significant for multiple amputations.

It is expected that the primary area this will impact on is in the provision of attendant care. It is anticipated that there will be a greater need for personal care assistance as well as domestic and community assistance. There may be significant transportation limitations as driving can be difficult to achieve in these circumstances.

Provision of an attendant care package should maximise independence through assisting and enabling the participant to complete daily activities. The maximum provision of hours upon discharge and in and ongoing capacity is estimated to be as follows:

- Personal care; up to 1 hour per day (7 hours per week) including showering and dressing, application of prosthesis (if applicable) and support to complete transfers.
- Domestic activities including laundry; up to 10 hours per week
- Community activities; between 2 and 4 hours per week
- Gardening activities; up to 2 hours per month

The Occupational Therapy Australia Independent Living Skill Assessment Guidelines can be used to provide specific recommendations in relation to attendant care provision.

It is anticipated that further home modifications, equipment provision and prosthetic training would influence the level of care required and the care package should be reviewed regularly.

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## Disclaimer

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Please note that these draft guidelines have been developed based on the author's clinical experience and knowledge base and a brief review of the literature. They should not be considered to be the accepted clinical practice to date nor LSA policy. An extensive literature review has not been completed and it should be noted that these guidelines are currently open for review.