



Transition in the Prosthetic Services

Clinicians Toolkit

A toolkit for clinicians to support children and families transitioning from children's to adults' prosthetic services.

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Toolkit background

What is this toolkit for?

This booklet is for clinicians working in UK prosthetic services. It has been created to help support children who use prosthetic services, and their families, in preparing for and completing their transition to adults' services.

What is transitioning?

Transition is the process of a young person moving from children's prosthetic services to adults' prosthetic services. This should be gradual and involve collaboration between children's and adults' services to ensure that transition is smooth and does not feel like a 'cliff edge' for the young person and their family.

Why was this toolkit created?

As identified by research conducted by LimbPower and Starworks, young people and their families felt there was a need for more information about the transition from children's to adults' prosthetic services. This would support clinicians in addressing the family's worries about aspects of the change, including: changes to the young person's responsibilities for managing their treatment, leaving behind relationships they have developed with their paediatric treatment team, forming new ones with their adult team and changes to their treatment and care. These concerns should be addressed starting at an early stage, usually when the child is around 11 years old, using age appropriate language and encouraging the young person to be increasingly involved in conversations and decisions about their treatment.

How was this toolkit developed?

This toolkit describes the identified challenges and barriers faced by young people and their families as they go through transition and identifies ways in which you can help to guide them through the process. Where one exists, a facilitator has been identified that can help to address each barrier. This toolkit also includes tips and advice to overcome each barrier identified.

Solutions gathered from the research conducted by LimbPower and Starworks, suggestions from the families, as well as other healthcare resources (listed in acknowledgements) were adapted to the needs of young people using the prosthetics services.

Challenges for young people going through transition

Through the research conducted by LimbPower and Starworks, a number of challenges for families with children going through transition were identified. A key underlying theme of this was a lack of clear, timely information provided to them about the process of transition and what to expect upon moving to adult services. Participants in the research highlighted the importance of clear communication at every stage of transition; with the child, their family and between clinical teams.

The table below identifies the overarching challenges or concerns for families, specific barriers associated with those challenges, facilitators identified in the research and suggestions or recommendations for clinicians to facilitate an improved transition experience.

Challenge	Barrier	Facilitator	Clinician's role
Transfer of responsibility from parent to child	Managing appointments, medication etc.	Taking a gradual approach to building a child's responsibility for their own healthcare	Toolkit section: Self-Advocacy and Transfer
	Need to repeat details of 'medical journey' to many different clinicians	Provision of clear and appropriate notes from medical appointments (from clinician to child)	Toolkit section: Glossary Ensure all communication involves the child and is understood by them
		Families and children given an accessible way of maintaining a written record of the child's 'healthcare journey'	Encourage use of the "My health journey" booklet
	Use of complex, unfamiliar medical terminology	Use of appropriate terminology and ensuring any complex/unfamiliar terms are properly explained/ understood	Coach young person in asking questions and self-managing



Challenges for young people going through transition (continued)

Challenge	Barrier	Facilitator	Clinician's role
Change of clinical setting(s)	Being in larger groups/settings for all kinds of activities	Visiting adult health services prior to transition	Toolkit section: Self-Advocacy and Transfer Explaining the plan for when they are an adult and meeting the adult team
Change of clinical team and support network	Concern about changes to level of care	Having a strong support network	Toolkit section: Signposting Community groups and charities for support
		Facilitating handover meeting between child and adult services team	Toolkit section: Glossary Self-advocacy and Transfer Explaining the plan for when they are an adult and meeting the adult team
		Making sure child is properly introduced to adult clinical team, knows their names and understands their role in the child's care.	Toolkit section: Glossary Self-advocacy and Transfer Explaining the plan for when they are an adult and meeting the adult team
		Assignment of a 'transition coordinator', an individual who can coordinate transition and provide a single point of contact for child during the process	We strongly encourage the allocation of a key worker/ coordinator
Change in available services	Lack of access to treatment that is available through child services e.g. activity limbs	Signposting to external support services	Toolkit section: Signposting
Other normal concerns for teenagers e.g: Change of school Puberty Social concerns Exams	Lack of education/ training for teachers	Developing positive relationships with e.g. teachers, coaches etc.	Clinicians can support with clear information about conditions and signposting Toolkit section: Glossary & Signposting
	Peer attitudes and reactions	The research also noted the positive impact for children of having access to other individuals who have been through transition, to answer questions about areas of uncertainty and support them through the process.	
	Changes to their limb as they grow/ develop		

How can clinicians help?

In a busy clinical environment, supporting families and young people as they transition to adults' services can be challenging. Here we have developed a few key pointers to support families and clinicians working together to guide this process:

- Talk to the young person**
Talk to the young person and family about their concerns and needs. We have included a section on 'How to support clear communication' in this booklet to support all steps of the process.
- Use their 'My Health Journey' booklet**
The use of a young person's 'My Health Journey' booklet to outline their condition and avoid repeated retelling of their medical history. This was identified by families in the research as a challenge.
- Make notes accessible**
Ensure that the young person has access to their notes and that these are written in a way that they can understand, and as they grow older that their notes are shared with them before their parents. Make sure that they are aware that they will need to update their contact details with the prosthetic services to enable this to happen.
- Use the questionnaires**
Use of Ready Steady Go (RSG) and supplementary Prosthetic Clinical Transitions Questionnaire (PCT), (both described in this booklet), to provide a structured way to identify their needs and guide conversations.
- Allocate a transition coordinator**
Allocation of a transition coordinator, if this is not a specific role in your trust then consider allocating the young person a key contact to support their transition. This should be someone with whom they already have a meaningful relationship.



How to use this toolkit

The Ready, Steady, Go (RSG) programme is a healthcare initiative that forms part of a transition and patient empowerment network. It is designed to support young people with long-term conditions to move from children's services to adult services. The programme focuses on building skills to allow progression towards self-management of the young person's treatment and condition.

We have created a supplementary questionnaire, the PCT, for use by the prosthetic services alongside the RSG programme. The PCT incorporates feedback from clinicians and families with children using the prosthetic services, to ensure additional specific aspects of care are considered.

To make use of the RSG process and supplementary PCT programme, follow steps 1-4 below:

Step 1 – Complete the RSG questionnaire

The young person is asked to complete the appropriate RSG questionnaire. The questionnaires are available on the Readysteadygo website and are included in the appendices.

RSG is split into four questionnaires with recommended age ranges and the appropriate questionnaire indicated for each below, although these are flexible and you should consider the individual's maturity and level of development.

- **Ready** – aimed at pre-teens, approximately 11 – 13 years old
- **Steady** – aimed at early teens, approximately 14 – 16 years old
- **Go** – aimed at teens, approximately 16 – 18 years old
- **Hello** – aimed at 18 year olds starting at their adult clinic

Please note, the young person may also be asked to complete the RSG questionnaires if attending other clinics.

Step 2 – Complete the PCT supplement

This can be found in Appendix 2 of this toolkit.

The PCT applies to all age groups, however, questions 11- 23 have recommended age ranges for when they should be introduced, although these are flexible and you should consider the individual's maturity and level of development.

Step 3 – Address any gaps

As a clinician, your primary focus is on any questions where the young person has responded "no," or where you feel their response needs further exploration. This toolkit offers support to help you address any gaps identified in each section of the questionnaire. The quick reference guide below highlights the relevant section of this toolkit to use when a gap is identified by a response to the questionnaire.

Quick Reference Table

Questionnaire Section	Toolkit Section
Knowledge	Knowledge or Glossary (Appendix 1)
Self-Advocacy	Self-Advocacy and Transfer
Health & lifestyle	Health and Lifestyle
Daily Living – School/Education and Your Future – Leisure	Support Pathway
Managing Your Emotions	Signposting
Communication	Effective Communication

Plan and review

Support move towards independence depending on level/version of RSG used (taken directly from RSG model)

- **Ready** – Young person and carers introduced to the concept of shared decision making and confidentiality. When they are ready, the young person is encouraged to be seen alone in clinic for a few minutes.
- **Steady** – Aim to see the young person on their own for longer in clinic. Carer fully involved. Duplicate clinic letters offered to young person.
- **Go** – Work towards young person conducting entire clinic alone. Keep carers involved. Referral letter sent to adult team and arrange for young person to meet with adult team where ongoing issues can be highlighted. Ideally aim for all issues to be addressed before transfer of care. Formal transfer letter written and goals agreed.
- **Hello** – Questionnaire is completed periodically* to ensure knowledge and skills are maintained. Any issues addressed and goals agreed.

In all cases it is recommended to set some goals to work towards together for their treatment and their transition.

*The frequency of review will depend on patient's individual needs and gaps in knowledge identified.



Top tips for a good transition

These top tips have been created based on transition information from several other sources including; NICE guidelines, The Scottish Transition Forum's Principles of Good Transitions, Bladder and Bowel UK and Asthma and Lung UK.

- 1 Start early**
Start early, transition is a process.
- 2 Be age appropriate**
Use age appropriate language that keeps the young person at the centre.
- 3 Help them take control**
Support confidence by encouraging the young person to take control of their own care.
- 4 Coordinate services**
Coordinate across services and consider joint appointments with adults' services to allow experience of both teams and locations.
- 5 Support the family**
Many parents find it hard to take a back seat. Gradual transition will support their understanding and acceptance of the changes happening.
- 6 Support emotionally**
Encourage peer and emotional support.
- 7 Communicate clearly**
Provide clear information to support the transition.
- 8 Consider the whole young person**
Consider the whole adult not just their transition to adult services, and signpost to additional support where relevant.
- 9 Don't assume**
Don't assume readiness at a given age, use assessment tools to identify support needed for an individual young person and their family.

Knowledge

If the young person does not have the required knowledge as identified in the questionnaire, ensure that this information is explained to them in an age-appropriate way. This section explores the differences between children's and adults' services and how to discuss medical services.

Changes from children's services to adult services

In most limb centres, a young person will continue to visit the same site and be treated by the same team. A few centres offer a different location and/ or team for adults' services. In all cases there will be some differences as they move into adult services. Some aspects of what will change between children's and adults' services may be immediately apparent while others will depend on local resources. Young people and their families are likely to have concerns about some of the differences. It is worth discussing any concerns that families have to prepare them for what will and won't be different.

It is important to listen to specific concerns and address the questions that arise, here are some common considerations (please consider specific changes for your services):

Change of team

Families can grow strong bonds with their clinicians and can be sad to say goodbye to a familiar team. It is important that they understand that the adult service team have adult-specific knowledge, which is what the young person will now need.

Change of location

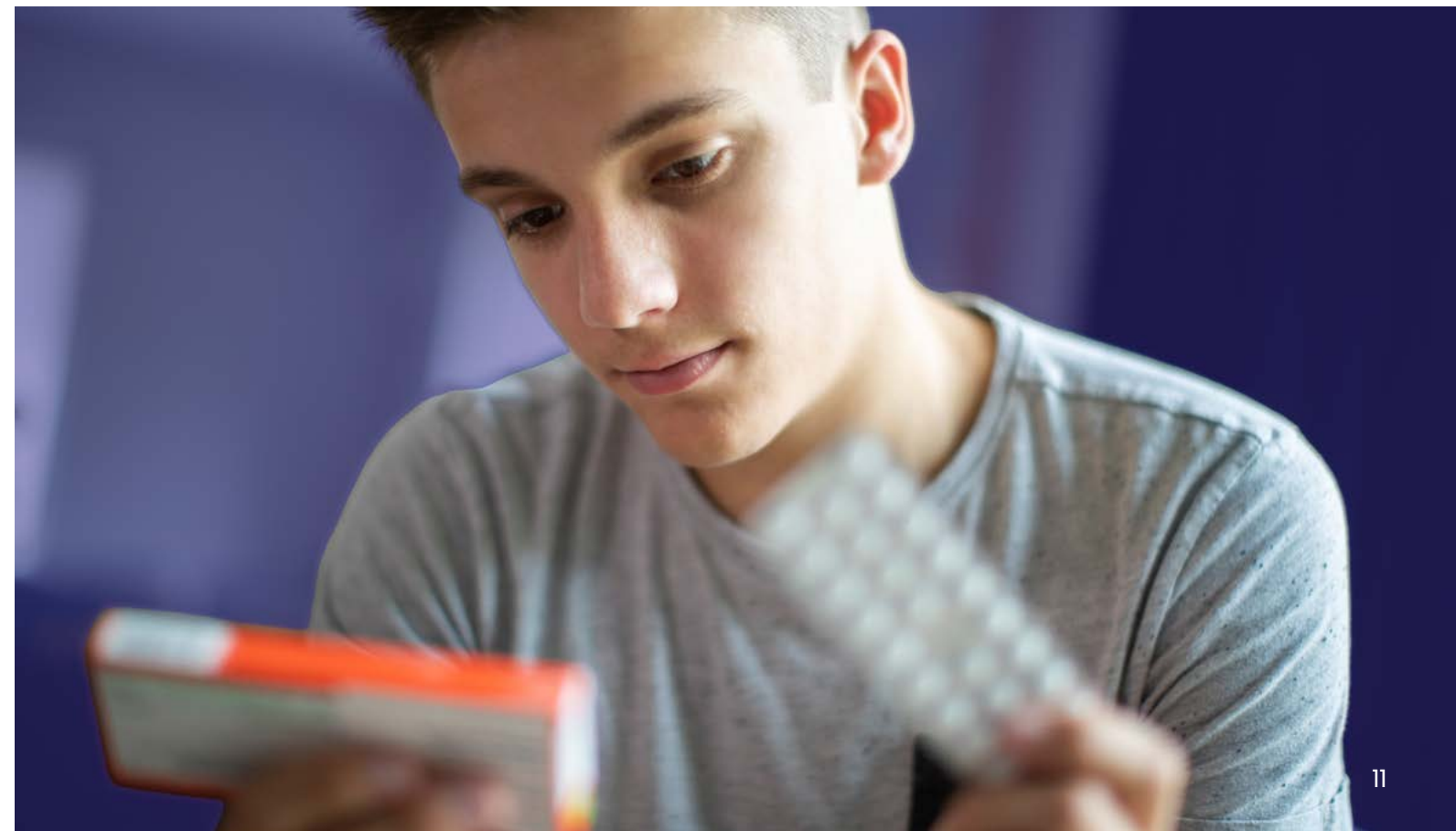
If they are moving from a small clinic to a bigger location, this can be very daunting, and they may fear getting lost. Walking with them round the new site and ensuring they are familiar with the department and how to get to it from the entrance will help acclimatise them to these changes.

Change to communal waiting areas

If the young person is used to a child-focused waiting area and clinic rooms, they should be aware of the more clean and plain environment of a hospital. It may be worth highlighting that this helps keep the area sterile. Many teenagers will be pleased to move from children's areas.

Change to shared treatment areas

It is also common in adults' services to share clinic rooms with other adults.



Changes from children's services to adult services (continued)

Loss of central point of contact

Families who are used to having one point of contact for all their care needs, might find that there are several points of contact for the different adult services. Wherever possible simplify this into a list of names, roles and contact details and ensure that the young person has been properly introduced to everyone on the list.

Fewer support staff

There can be concerns about access to support services, especially for counselling, community services, and safeguarding. In many areas there are more services available for adults, but this may depend on the specific services and location of the family.

Less frequent follow up

The NHS prosthetic service provision outlines that young people with an upper or lower limb prosthesis should be reviewed every 12–24 months. For adults this may be 3–5 years. Although this can sound alarming, it is worth reminding the family that this is the review time if there are no issues raised, that the young person should raise any issues with their centre and can arrange appointments and fitting reviews as needed. (It is also worth noting that NHS provision can change and this may change the availability of the components a young person is used to).

Longer waiting times

Many parents worry about longer waiting times in adult services, especially if they are used to priority appointments for children which will no longer be available in adults' services. Some locations have more appointment slots available to adults which can give the young person more flexibility about when they can attend. They should also be made aware if emergency appointments are possible and in what circumstances they will be made available.

Reduced access to sports limbs

There is no standard funding of sports limbs for those aged 18 or over, this can be a real concern for active young people. Sports limbs are no longer routinely prescribed past this age, but that does not mean they are not an option. Clinicians should discuss options with the family and ensure they are given the most opportunity to access devices before they turn 18, use of this limb can then be used to support clinical need in adult services.

Adults' services also have more:

More options

There are often more types of limb and more complex components available in adult services. The extra weight of these devices may have made them unsuitable for a younger child.

More independence

Young people have more of a say in what their personal goals are, what support they want, and what support they need.

More personalised

Parents often feel that children's care can include a generic plan to support school activities, as they enter adult services their long term goals and needs may be better considered.

Explaining access to sports and activity limbs in adults' services

Children and young people (up to 18 years old) were given access to activity and sports limbs thanks to LimbPower's work with the Department of Health and Social Care. To get a sports limb, families have to work with their clinicians to show a need for the limb. If they are a professional athlete they will need to talk to the governing body for that sport as high level/professional sports limbs cannot be provided on the NHS.

Once a patient reaches 18 and enters adults' services, sports limbs are not routinely provided on the NHS. Activity limbs or adaptation of their prostheses may be considered to help them take part in fitness or physical activities, but are less commonly available as they are in children's services. The clinical team need to discuss the options, how they fit into the provisions available, and if they consider the young person is going to make full use of the limb.

If a young person already has a sports limb, it is important to start planning when they will get their final sports limb before transfer into adult services and what the plan for the limb will be after they enter adult services in terms of maintenance and what happens when the socket no longer fits. If a young person does not yet have a sports limb it is worth now discussing their need for such a limb and training on it before reaching 18 years old.

Talking about medication and pain management

This may require referral to the prescribing clinician. Ensure communication about medication and pain management is clear and done in a way that supports the young person in remembering to take their medication as prescribed and identifying when they need further support. The young person should also be taught to understand what any medication does and any side effects it may have.

It is also worth considering whether or at what stage the young person could start taking responsibility for ordering repeat prescriptions.

The UK Department for Education encourages that, in a school setting, "children who are competent should be encouraged to take responsibility for managing their own medicines and procedures."

Alongside referral to pain management services, www.paintoolkit.org is a free online resource created by clinicians and patients, that offers practical advice for patients.



Support from children with a similar condition

Great benefit has been seen from peer support, young people may benefit from connection with charities which offer peer connection and support – See **Signposting**.

Contacting the prosthetics services (or other medical services)

Guidelines from gov.uk, NICE, and NHS England encourage empowering young people to manage their own health and appointments where possible.

To support this there must be youth-friendly environments, clinicians should promote self-referral pathways, and use clear age-appropriate communication.

- Ensure the young person knows how to contact the service and who to ask for
- If possible introduce them to the team that will answer a phone call/communication
- Give access to self-referral options
- Provide Health Information Passports so families do not need to repeat themselves.

Try this!

A practice call/communication with the young person.

Let them try with or without a script and in the same room or the room next door to the team they are contacting.

Talking about the impact of the condition in the future

If the young person has responded 'no' to the question 'I understand what is likely to happen with my condition when I am an adult' in the 'Go' questionnaire, this may be a good opportunity for the clinician or therapist from adult services to talk with the young person about their condition and how it may develop in the future.



Self-Advocacy and Transfer

The young person will need ongoing support and information to prepare for the move to adults' services. This section explores what transitioning is, shared decision making and top tips to allow clinicians to support children preparing for transition.

Explaining transition to young people

We recommend explaining what transition means to children using something like the description below, making sure they are aware of the key changes that will occur to their care, giving some idea of the timescale and sharing the positive aspects of transitioning:

In healthcare, the word 'transition' is used to describe the process of preparing, planning and moving service, in this case, from children's to adults' prosthetic services. This is not a single event, it's a gradual process that gives you, and everyone involved in your treatment, time to get you ready to move to adults' services and understand what your prosthetic treatment needs as an adult are likely to be.

Transition is about making plans with you – not about you, as you start to be more involved in decision making about your care. You may have some worries about the process but hopefully, by following the advice in this booklet and getting involved in the transition process, you will feel more happy and confident about the move as you gain independence and a better understanding of your treatment and condition. This will make sure you are ready to flourish in adult life.

Explaining 'Ask 3 Questions' and shared decision making

Shared decision making is an important part of self-advocacy in healthcare decisions. It involves collaboration between the expertise of the clinician, and the lived experience and personal desires and needs of the patient. Together, you can then work towards making the best decisions for the care of the individual.

Ask 3

Questions

1

What are my options?

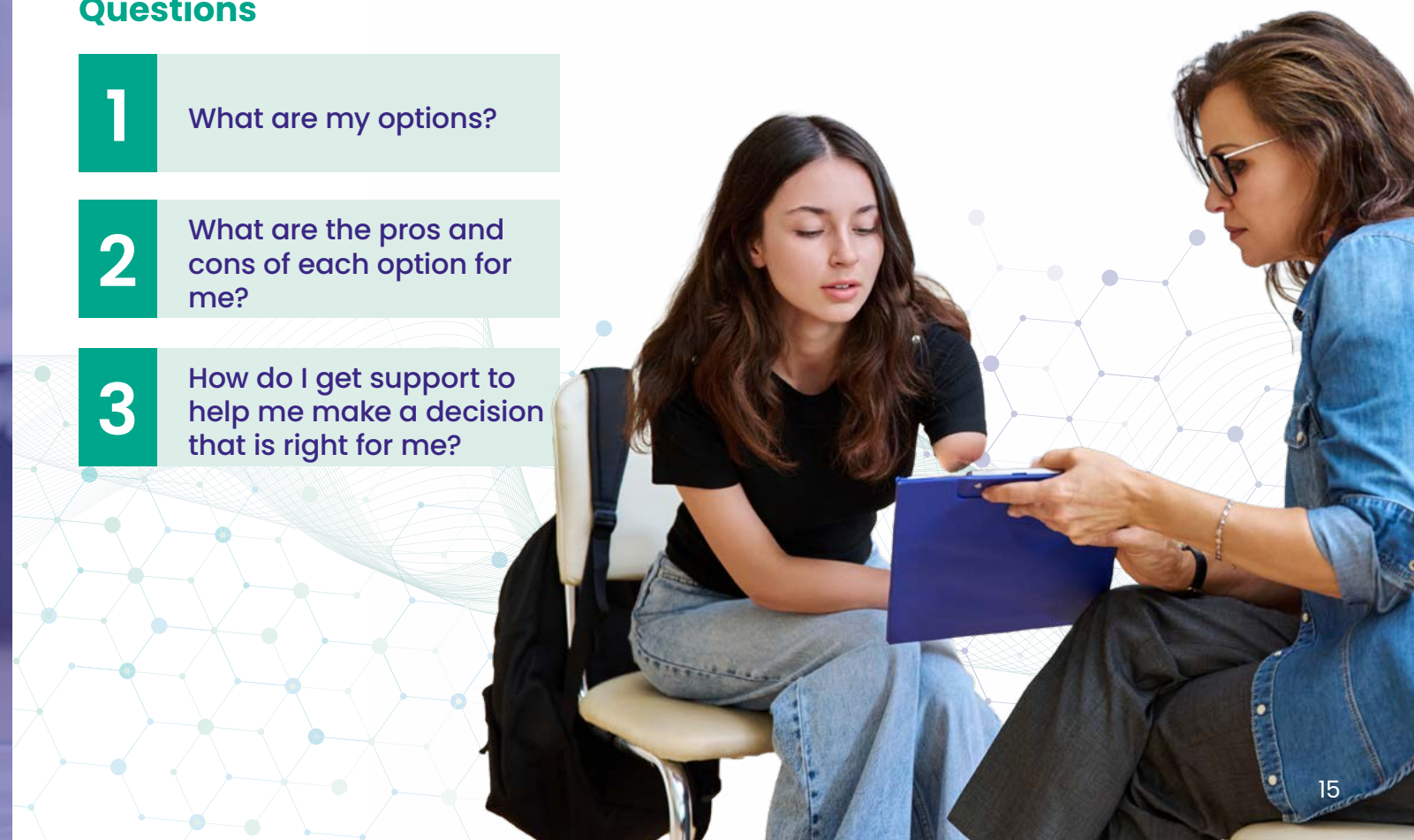
2

What are the pros and cons of each option for me?

3

How do I get support to help me make a decision that is right for me?

'Ask 3 Questions' has been created by the Health Foundation as part of a UK based, patient-focused initiative to support shared decision-making, helping patients and clinicians to work together to decide on the best course of action. When faced with a decision about their treatment or care, patients are encouraged to ask:



Self-Advocacy and Transfer (continued)

Explaining how personal information is transferred

While each trust will likely have its own process for transferring information, where a gradual, planned transition is used, the process of information sharing usually starts around age 14 where key health info is summarised in documents like Health Information Passports; these are shared securely between teams, and eventually given to the young person to manage.

NB: Transition is a process, while transfer often refers to a single event such as all your medical history being transferred in one go.

Explaining the right to confidentiality

Children and young people have a right to confidentiality, this is essential for building trust and the effective provision of care. Teenagers may be particularly concerned about keeping confidential information from their parents/carers. Without the assurance that information they share will be confidential, children and young people may be reluctant to seek medical attention or provide information to clinicians that they need to provide good care.

As outlined in the General Medical Council (GMC) guidelines, the right to confidentiality for children and young people is not absolute. Information should be shared in certain circumstances; where it is required by law, if the person to whom the information relates (or their parent/carer if they do not have the capacity) has consented to the information being shared, or if it is justified in the public interest. The appropriate sharing of information is important in the provision of care for children and young people and clinicians should feel confident acting on concerns about potential neglect or abuse.

In law, anyone with mental capacity*, over the age of 16 is considered able to make medical decisions for themselves (Family Law Reform Act 1969). In England and Wales, parents have residual rights (access to medical records and the right to intervene in medical decisions) until a child is 18 years old and is considered an adult. In Scots law at 16 years old a person is considered a full adult (Age of Legal Capacity (Scotland) Act 1991). Once an adult, individuals have the right to consent to or refuse all medical procedures and treatments independent of parental opinion.

*In all other cases, the Mental Capacity Act 2005 applies.

Do you know your rights?

Explaining the plan for when they are an adult, and meeting the adult team

Ideally, a key worker or transition coordinator will be allocated to the child to support transition, however, if this is not the case, a collaborative approach should be taken between the family and prosthetic service clinician ensuring that:

- The young person's concerns and goals are discussed with their involvement
- The young person is introduced to the team that will be involved in their adult care
- A timeline is created for actions needed and a date for final transition

It can be hugely beneficial to arrange joint treatment sessions. Remember a big team can be overwhelming for a young person so starting with a session where the equivalent clinicians from both children's and adults' services are present at the children's clinic, and progressing to a visit to the adult clinic where the child can be slowly introduced to each member of the team one at a time can be beneficial.

Top tips to support independence

1

Start small

The young person could be encouraged to:

- Ask one or two questions that they have (these could be planned in advance)
- Try to answer questions from the clinician first, before deferring to a parent
- Have part of the session where the parent or carer remains quiet or sits outside
- Try and explain back to a second parent or relative what they learnt in a session to improve their confidence retaining and repeating information provided.

2

Listen to the young person's concerns, encourage them to share honest emotions

Ensure the young person is aware that it is ok to feel anxious or scared and that you will all work together to support them. Try and explain back to a second parent or relative what they learnt in a session to improve their confidence retaining and repeating information provided.

3

Support parents to take a step back

Encourage parents to move from:

- "Speaking for" their child to being "available to support" the young person
- "Organising" (appointments etc) to "reminding"
- "Scheduling" to "Encouraging formation of habits".

4

Embrace technology

Young people may be better at using technology to manage information and appointments than their parents. Encouraging the young person to "teach" or "support" their parent or carer to use technology for medical needs may support transition.

5

Have some trial runs

Parents, carers or clinicians can try role-playing in a safe environment. You can role-play any scenario; e.g. a phone conversation to make an appointment, explaining prosthetic limb fit issues, asking a clinician for support on wheelchair use.

6

Encourage teamwork but let the young person lead

Some young people will feel they want their parents with them for longer and some parents might feel excluded as their child becomes more independent. It is important to ask the young person to discuss their preferences and gradually learn confidence to voice their opinion.

7

Encourage independence outside of the clinic

Some simple tasks like shopping alone, organising an overnight stay, or booking their own driving lessons can support independence and these skills can transfer to clinical sessions.

8

Resistance may need time or further review

While some children do just take longer, there may also be underlying reasons that a child needs additional support to become independent. Encouraging dialogue is the best way to identify such reasons.

Health and Lifestyle

The young person may need support in understanding some basic health and wellbeing factors. Below we have provided some starting points or prompts to further discuss the health and lifestyle aspects of the questionnaire with the patient and family. These are not intended as scripts, you are best placed to understand what is relevant to your patient.

Please use your clinical judgment if more or less explanation is needed or if signposting is more appropriate.

Questionnaire area	Simple explanation
Exercise and Physical Activity: The importance of physical activity, following prescribed exercises and getting support to participate in sport.	Exercise and physical activity is important for everyone, all children under 18 should be getting at least 1 hour of physical activity every single day to keep you strong and healthy. It makes your muscles and bones stronger, improves your heart and lungs, and even makes you feel happier. When you have a limb difference, staying active is even more important, as you might have to use some muscles and body movements a little differently to other people. Being active is also really good for helping you understand your body, how it moves, and to feel confident in it. If you're not sure what activities are best, you can talk to your doctor or physiotherapist, who can help you choose exercises that are safe and fun. For more information refer to the Moving Medicine website, The 1 minute conversation. <i>NB: For young people who need more support in their prescribed exercises refer to the prescribing clinician.</i> <i>If more support is needed in identifying suitable sports and physical activity refer to signposting section for organisations such as LimbPower.</i>



Questionnaire area	Simple explanation
Availability of sports limbs:	You might currently have a sports limb from the NHS that you wear every day or that you put on when you do sports. Once you turn 18 and enter adults' services, sports limbs are no longer provided by the NHS. Activity limbs (which are different to sport-specific limbs) or adaptation of your prostheses may be considered to help you take part in fitness or physical activities, but these are less commonly available than they are in children's services, and you should talk to your clinical team about the options. <i>NB: More information on this can be found in the Knowledge section.</i>
Alcohol, drugs and smoking: What are the risks of alcohol, drugs and smoking to my health?	Taken from Better Lives, Healthy Futures: It is important to make well-informed and safe choices about alcohol, nicotine and drug use. Recreational drugs and alcohol can affect your physical and mental health in lots of different ways. People may drink alcohol or take substances with no long-lasting effects. They may enjoy the feelings of confidence, energy or relaxation that drugs, nicotine and alcohol can bring at the time, or it may be part of trying a new experience and fitting in socially. However, drugs or alcohol can also be used by some as a form of self-medication or as a coping mechanism to deal with difficult or painful feelings. Even if it seems to help at the time, in the long term, drugs, nicotine and alcohol can make difficult feelings more painful, and can make existing mental health conditions worse. Drug and alcohol use can affect our judgment, leading to risky behaviour. Becoming addicted to substances is also a risk. If someone becomes addicted to alcohol, nicotine or drugs, they can become so focused on feeding their habits that engaging with learning or socialising becomes difficult. Drugs and alcohol could also interfere with existing prescribed medication For more information see NHS website: Better Lives, Healthy Futures.
Diet and Eating: What does appropriate eating mean for my general health?	Eating the right foods helps your body stay strong, healthy, and full of energy. It means trying to have a good mix of different foods, like fruit, vegetables, whole grains (such as brown bread, rice, or pasta), and proteins (like meat, fish, eggs, beans, or nuts). When you eat well, your body can grow properly, you feel better, and you can do all the things you enjoy, like running, playing sports, or spending time with friends. Good eating also helps you concentrate at school and keeps your skin, hair, and bones healthy. It's okay to have treats now and again, but eating too many sugary or fatty foods can make you feel tired or unwell. Drinking enough water is important too! If you ever have questions about what foods are best for you, you can talk to a trusted adult, like your doctor, nurse, or a family member. They can help you make choices that keep you feeling happy and healthy. For more information see the NHS Eatwell guide.



Questionnaire area	Simple explanation
Development & Puberty: How can my condition affect how I develop (e.g. puberty)?	You will go through puberty, and most of the signs and symptoms will be the same as your friends and others in your age group. This is the time your body starts changing into a biological adult. If your condition affects the growth plates in a limb you may notice more differences between your limbs, or between your growth and that of your friends. But that's ok, everyone grows at their own rate. Teenage hormones can also be challenging; this is something that everyone goes through and for all of us it can make us feel like the things that make us different really stand out in a bad way. It's important to remember that we are all different and that's what makes life interesting, and that this time of hormones will pass. Hormones may also affect residual limb volume fluctuations. For example, during menstruation you may experience changes in the volume of your residual limb which require adjusting your sock management to maintain a good prosthetic limb fit. You might find that you have feelings of anger, or shyness, or confusion and it can be difficult to explain these to others. This is a good time to reach out to support groups and communities of other people who have had similar experiences to you. For more information on puberty visit NHS Healthier Together
Sexual Health: Where can I access reliable information about sexual health?	See Signposting section
Pregnancy & Parenting: What are the implications of my condition on pregnancy/ parenting?	It is important to understand that having a limb difference or amputation doesn't stop you from being a brilliant parent. Most people with limb differences and amputation have healthy pregnancies at the same rate as the general population. It is possible that during pregnancy, you might need to make a few adjustments, especially if you use prostheses or mobility aids, as your body changes and where you are carrying the baby changes how you move. Healthcare professionals such as your GP, midwife, or occupational therapist will be able to support you and help you adapt. When it comes to parenting, you may need to find new ways to do some tasks, such as feeding, changing, or carrying your baby. Remember, lots of people have been there before you and talking to others will give you loads of ideas. Support groups and organisations for people with limb differences can be great sources of advice and encouragement.
Function & Feeling: How could my condition affect how I feel and function e.g fatigue, time to complete tasks, aches and pains	This is dependent on the cause and type of amputation or limb difference, so use clinical knowledge or refer to an appropriate clinician. It may also be appropriate to signpost to peer support through charities or other support groups. Consider factors such as: ■ Fatigue - additional energy required to complete activity compared to peers ■ Slower movement - Longer to complete tasks, keep pace with peers ■ Aches and pain - Strain on other parts of the body ■ Residual limb and phantom pain ■ Non limb wearing days ■ Emotional impact

Support Pathway

The young person will need ongoing clinical support as they take on more adult skills and tasks. This section supports the use of clinical judgment for decision making and ensuring the right support is put in place.

There may be many reasons why a young person is not yet able to answer yes to all these questions. You can use your clinical judgment to identify if this is something that can be addressed in clinic.

Here we recommend a simple approach:

- First explore the issue. Why have they answered no?
 - If the reasons are not condition-based, this may be something for parents to explore with teachers or through signposted services
- If the reasons are condition-related, explore what type of reason is stated and identify the correct service to support learning and facilitating in this area.

Type of barrier or concern identified	Suggested clinical support required
Physical or Functional (i.e restrictions in their ability to perform a task which are related to the limb difference)	Occupational therapist or Physiotherapist
Accessibility of a location or proper forward planning	Occupational therapist
Equipment	Occupational therapist
Prosthesis or prosthesis related equipment	Prosthetist
Orthotic(s)	Orthotist
Systemic (i.e. related to internal bodily function and not directly related to the limb difference)	Consultant/Nurse
Prognosis	Consultant/Nurse
Benefits and Careers	If no suitable staff in clinic refer to signposting section

If any safeguarding issues arise, please use trust processes or see **Signposting > Safeguarding** section. Consider **Signposting** section for other items raised which are not covered in-clinic.



Signposting

Much of the advice, information and treatment that you offer will help a young person better understand their body and their potential. Additional support may be necessary.

Some services may have counselling or support services on-site. Where this is not available, it may be necessary to refer to external services.

This section includes suggested organisations to signpost children and young people to for information and advice on issues relating to mental and sexual health as well as charities and community organisations which offer support targeted at those with limb conditions. We have also included signposting suggestions for advice and information on safeguarding. This isn't an exhaustive list, but includes some popular UK suggestions, there is also space to include information about local organisations providing services in your area.

Some families may also benefit from being made aware that private services are available which may offer alternative options for prosthetic limbs.

Community groups and charities for support

Charities offer peer support to allow better understanding of your condition, how to communicate with others about your condition, and a safe space to ask questions. Some charities also offer careers advice.



LimbPower

A charity which supports young people with any form of limb loss or difference through community links, outreach, peer support, social inclusion and resources for healthcare professionals, schools and families, bridging the gap between hospital rehab and active community life to improve physical, social, and mental well-being. They also provide inclusive social, educational and sports events like the Junior Games and practical fundamental skills workshops to build confidence with or without a prosthesis.



SteelBones

A charity which supports young people with limb loss or difference, and their families and support network, through dedicated programmes that include peer support, confidence-building activities, and family-focused resources.



Reach

A charity which supports young people with upper limb differences by providing a strong community network, fun activities, practical advice, and emotional support, helping them build confidence and realise their potential without limitations.



Steps Charity

supports families and individuals affected by childhood lower limb conditions, providing information, emotional support, a helpline, and peer support to help navigate diagnosis and treatment, to support everyone to reach their full potential.

Mental health

Alongside NHS Child and Adolescent Mental Health Services (CAMHS), the following charities offer support to children and families...



Young minds

A mental health charity for both young people and their families.



Shout 85258

Free and confidential texting service for those struggling with mental health.. Available to anyone at any age, you can text "Shout" to 85258 to start a conversation or visit their website.

Bullying



The Anti-Bullying Alliance

Set up by the NSPCC and National Children's Bureau to bring together organisations and individuals working to combat bullying. They provide advice and information on how to find appropriate support if you are being bullied. Their members include anti-bullying charities, organisations with a substantial remit to tackle bullying, schools/colleges and individuals and organisations that support their vision.



Kidscape

A UK charity who provide advice and resources for young people and their parents about bullying.

Sexual health

Young people aged 13+ have the same rights to confidentiality as adults and so should be able to contact services without parental support or their parents being informed against their wishes.

Alongside services available through the NHS and local GP, some schools offer confidential sexual health advice sessions.



Sexual Health

NHS Sexual-health

Offer information on sexual health, including; where to go for advice, information about confidentiality, visiting a clinic, advice for gay, lesbian and bisexual people and sex activities and risk.



Brook Young People

A charity which offers clear information and links to services for people under the age of 25 in the UK.

Here is space to add signposting links in your local area.

Turn2us

A UK national charity that helps people facing financial hardship by providing free tools and information to find money they're entitled to, such as benefits and charitable grants, aiming to end financial insecurity.

Citizens Advice

This service helps people with benefits by offering free, confidential advice on checking entitlement, understanding complex rules, filling out forms (especially for Universal Credit), appealing decisions, and finding extra support for low income, disability, housing, or work issues, available online, by phone, or in person. Available to anyone at any age, you can text "Shout" to 85258 to start a conversation or visit their website.

National careers service

Supporting disabled young people (13+) by offering free, impartial guidance on education, training, and work, with advisers considering their specific needs and signposting funding like Access to Work, helping with CVs, interviews, and exploring suitable roles, often working with school SENCOs to bridge the gap from learning to employment.

- For Scotland - My world of work- skills development
- For Wales - Careers Wales
- For Northern Ireland - Careers service Northern Ireland.

National Society for the Prevention of Cruelty to Children (NSPCC)

Offer a specialised helpline for advice or take action when a concern is raised.

How to Ensure Effective Communication

In this section we have summarised key elements from the guidelines provided by the General Medical Council (GMC) and Patient Information Forum (PIF) on effective communication with children and young people and the creation of health information for this patient group as they begin to take responsibility for their own care.

Age-appropriate communication

Most 8 - 11 year olds can understand detailed information sufficiently to:

- Pull out key themes
- Ask clarifying questions
- Make judgments and express their opinions and share ideas
- Process new information to change their ideas

They engage well with question-and-answer approaches, using simple questions they have posed or a caregiver has posed. Try highlighting facts using phrases such as "This is an amazing fact .../did you know...?"

Most young people aged 12+ are able to process more information and can:

- Begin to assess and verify the reliability of information
- Begin to identify bias
- Form independent opinions and share these opinions
- Understand complex concepts (if explained clearly)
- Search for their own information sources online.

They are more likely to lead question sessions. This group will also likely engage well with online information, if they have access to it.



General approach

A general approach is recommended by the PIF, we have adjusted this as follows:

1. Establish what the young person wants and needs to know
2. Listen to them and respect their views. Ensure you talk to the young person directly where possible
3. Provide information at the right level for their age and maturity (this may be guided by the family, the young person, and your clinical judgment)
4. Use language they can understand, try to find alternative wording if they don't initially understand
5. Consider the impact of surroundings and non-verbal communication
6. Remember to pace the information, not all updates need to be given in one session, as this may be too much at once. Information will also need to be repeated to ensure retention
7. Check understanding regularly to identify if your communication needs modifying
8. Involve their parents or carers as appropriate
9. Honesty is crucial, aim to be reassuring but truthful. If appropriate, ensure you give clear information of the chances of success and risks involved with different types of treatment/no treatment
10. Do not make assumptions about knowledge and understanding
 - a. Check what the young person already knows
 - b. Assess any misunderstanding and correct this in a supportive manner
11. Methods such as 'teach back' ("Explain to me what you understood from our chat") can help professionals ensure they have communicated clearly.

In general, people prefer to receive patient information directly from a healthcare professional (HCP). Parents expect HCPs to give them information rather than looking up information or reading leaflets themselves.

Remember, your main aim is not to expand their vocabulary but rather their understanding of their situation and future.

Advice from the PIF:

- "Diversity and the particular needs of your audience must be taken into consideration. Consider language, culture, social needs, disability, sexual orientation, gender and literacy, as well as age and information preference."
- "Involve parents, carers and other family members significant to the child or young person."
- "Always include clear signposting to more information, advice and support".

Appendix 1: Glossary

This glossary lists; the clinical roles, conditions and surgery types, and common technical terms to support conversations in an age appropriate way. These lists are not exhaustive and may be tailored to the needs of your patient and local services. Please use your clinical judgment if more or less explanation is needed or if signposting is more appropriate.

Clinicians and members of the healthcare team

Term Used	Description
Clinical Psychologist	A professional who helps you manage the emotional and mental challenges of dealing with limb-loss or limb difference
Clinician	Anyone who works in healthcare and provides a service to patients
Consultant	A specialist trained doctor with particular knowledge and experience treating people with amputation/limb difference
Counsellor	A professional who provides emotional support and helps you talk through feelings related to amputation or limb difference.
General Practitioner / GP	The doctor who is responsible for day-to-day medical care
Limb Centre Nurse	A nurse who provides specialist nursing care and support as part of the limb centre team
Occupational Therapist / OT	A person who helps you adapt to having an amputation and/or limb difference by making changes to your home/school/work environment
Orthotist	A person who designs, makes, and fits any orthotics (custom made support wear such as brace, splints or adapted footwear)
Physiotherapist / Physio	A person who helps you gain strength, mobility and independence through exercises and advice on things like pain management and stump care
Podiatrist	A healthcare professional who specialises in care and treatment of the foot and ankle
Prosthetic Technician	A person who helps the prosthetist make, put together and repair your artificial limb (prosthesis)
Prosthetist	(Pronounced "Pross-thuh-tist"). A person who designs, makes and fits your artificial limb (prosthesis)

Conditions or surgery

Term Used	Description
Amputation	Where part or all of a leg or arm is removed, usually to help you move better or to take away pain
Bilateral Amputation	Where amputation is on both left and right limbs (either arms or legs)
Hemipelvectomy	Through the hip area (pelvis), this is removal of the leg from the pelvis to the toes
Hip Disarticulation / Through Hip Amputation	Through the hip joint, this is removal of the full leg
Multilimb Amputation	Where sections of more than one limb have been amputated
Phantom Limb Pain	Where you can feel pain in the part of your limb that has been removed, this may need treatment
Phantom Limb Sensation	Where you can feel sensations in the part of your limb that has been removed, like wiggling your ghost fingers or toes, this should not hurt
Proximal Femoral Focal Deficiency / PFFD	A condition you are born with (congenital) that causes the thigh bone (femur) to not develop fully (often shorter than the leg on your other side)



Conditions or surgery (continued)

Term Used	Description
Quadruple amputation	Where sections of both legs and both arms have been amputated
Residual Limb Pain	Pain felt in the part of your limb that remains after an amputation, such as the skin, muscles, nerves or bone
Rotationplasty	Literally a surgical repair involving rotation. Often this is where your calf bone is removed and your ankle is turned around and joined at your knee so you can use it as a knee joint and move more easily.
Symes/Through Ankle	This is removal of the foot from the ankle to the toes
Through Knee Amputation	This is removal of the leg from the knee to the toes
Through Wrist Amputation	This is removal of the hand from the wrist to the fingers
Transfemoral / Above Knee Amputation	Through the thigh bone (femur), this is any removal of the leg from above the knee to the toes
Transhumeral / Above Elbow Amputation	Through the upper arm bone (humerus), this is removal of the arm from above the elbow to the fingers
Transradial / Below Elbow Amputation	Through the forearm bone (radius), this is removal of the arm from below the elbow to the fingers
Transtibial/ Below Knee Amputation	Through the calf bones (tibia and fibular), this is removal of leg from below the knee to the toes

Technical or medical terms

Term Used	Description
Acquired	A condition or event that occurred after birth leading to amputation such as trauma
Activity Prosthesis	Specially made artificial limb(s) that allow you to participate in sport or other activity more easily e.g. running blade
Congenital	A condition that you had when you were born
Gait	The way that you walk
Limb Difference	Having one or more arms and/or legs (limbs) that are absent or which work differently or have grown differently to other children of the same age. This can be something you are born with or something that happened during your lifetime.
Liner or Socks	These are worn on your residual limb, like a big sleeve (or sock) to help protect the residual limb, usually when it is inside the socket. These can also be used to help make the socket fit better
Lower Limb(s)	Leg(s)
Medication	Medicine
Orthotics	Devices that you wear to support your body and how it moves, such as braces, splints, or special footwear.

Term Used	Description
Paediatric	Children’s medical services
Prosthesis / Prosthetic Arm / Prosthetic Leg	(Pronounced “Pross-thee-sis” or “Pross-thet-ic”) An artificial leg or arm (limb).
Residual Limb	The part of your amputated limb that is above the amputation. Also called a ‘little leg’ or stump. If you don’t have an amputation, this will mean the limb that is shorter or has grown differently.
Socket	The part of the prosthesis that fits over your body at the residual limb, this connects you to your prosthesis
Socket Comfort	How comfortable your socket feels on your limb, both when stationary and when moving and being active
Socket Fit	How well the prosthetic socket matches (fits) over the residual limb to ensure it is comfortable, stable and functional, ensuring that the weight from and on the body is being properly supported. When a socket doesn’t fit anymore you may be asked to use more socks or have a new socket made.
Suspension	The system by which your limb stays firmly attached to your body so that it doesn’t slide off
Transition	The process of moving from children’s services to adults’ services
Upper Limb(s)	Arm(s)



Appendix 2: How to respond to the PCT Questionnaire

How to Respond to Supplementary Prosthetic Clinical Transitions (PCT) Questionnaire.

Question	Where to look if they answer no
Knowledge	
I can describe my condition and my type of limb difference or amputation	Glossary
I know about pain management, including where to go, what to do, and I feel confident in determining if it is an emergency or not	Knowledge Talking about medication and pain management
Health and Lifestyle	
I understand the exercises that have been given to me and how they impact my condition	Health and Lifestyle Exercise and Physical Activity
I know sports and physical activities that I enjoy and can take part in	Health and Lifestyle Exercise and Physical Activity
I am aware that my condition can affect how I develop e.g. How I grow/volume changes due to hormones	Health and Lifestyle Development and Puberty
Daily living-school/education and your future - leisure	
I know what equipment I need to look after myself at home/ make snacks	Support Pathway
I know how to look after and clean my prosthetic limb/ liner / other devices	Support Pathway
I know what I need to pack to manage my condition and devices when I am away from home overnight	Support Pathway
I know about additional equipment I need to manage at school	Support Pathway
I know about additional equipment I need to use public transport and access my local community	Support Pathway

Additional questions -The following may be introduced when they are suitable/ relevant for the young person aged 14+

Question	Where to look if they answer no
Knowledge	
I know the names of the devices I use and can explain how my prosthesis works	Glossary or Support Pathway
I call the prosthetics department/limb centre myself if there is a query about my equipment and devices I need	Knowledge Contacting the prosthetics services (or other medical services)
I understand how access to sports limbs changes once I turn 18	Knowledge Changes from children's services to adult services
Self-advocacy and transfer to adult services	
I am aware of the changes in services available to me when I am an adult	Self-Advocacy and Transfer Explaining the plan for when they are an adult and meeting the adult team
Health and Lifestyle	
I have found exercises/sports/activities which I can take part in and I exercise regularly/have an active lifestyle	Health and Lifestyle Exercise and Physical Activity
I understand that sports and activity limbs are less readily available in adult services	Health and Lifestyle Availability of sports limbs
Daily living-school/education and your future - leisure	
I know how to look after and clean my prosthetic limb/ liner/other devices	Support Pathway
I understand how to look after my residual limb including when I am being active	Support Pathway
I understand how to look after my prosthetic limb/device including when I am being active	Support Pathway
I know what I need to pack for a trip away to ensure I can care for my residual limb and prosthesis	Support Pathway or Signposting Communities groups and charities for support
I understand when it is and isn't appropriate to wear my activity/sports limb	Support Pathway
I have been taught how to properly use my activity/ sports limb	Support Pathway
I know what I need to pack to manage my condition and devices for overnight and longer trips	Support Pathway



Appendix 3: How to respond to the Ready Questionnaire

Question	Where to look if they answer no
Knowledge	
I can describe my condition	Glossary
I know when to take my medications, names, doses, how often, etc.	Knowledge Talking about medication and pain management or refer to prescribing clinician
I know who's who in the medical and nursing team	Glossary
I understand the differences between children's and adult health care	Knowledge Changes from children's services to adult services
I know about resources that offer support for young people with my condition	Knowledge or Signposting Communities groups and charities for support
Self advocacy (speaking up for yourself)	
I feel ready to start preparing to be seen alone for part of the clinic visit in the future	Self Advocacy and Transfer Explaining the plan for when they are an adult and meeting the adult team
I ask my own questions in clinic	Self Advocacy and Transfer
I have heard and know about 'Ask 3 Questions'	Self Advocacy and Transfer Explaining 'Ask 3 Questions' and shared decision making
Health and Lifestyle	
I understand it is important to exercise for my general health and condition	Health and Lifestyle Exercise and Physical Activity
I understand the risks of alcohol, drugs and smoking to my health	Health and Lifestyle Alcohol, drugs and smoking
I understand what appropriate eating means for my general health	Health and Lifestyle Diet and Eating
I am aware that my condition can affect how I develop e.g. puberty	Health and Lifestyle Development & Puberty
I know where and how I can access reliable information about sexual health	Signposting
Daily living	
I can look after myself at home in terms of dressing and bathing/showering etc	Support Pathway
I can make my own snacks/meals	Support Pathway
I am able to be away from home overnight	Support Pathway

Question	Where to look if they answer no
School and your future	
I am managing at school e.g. getting to and around school, school work, PE, friends, etc	Support Pathway
I know what I want to do when I leave school	Support Pathway
Leisure	
I can use public transport and access my local community, e.g. shops, leisure centre, cinema	Support Pathway
I see my friends outside school	Support Pathway
Managing your emotions	
I know how to deal with unwelcome comments/bullying	Signposting Bullying
I know someone I can talk to when I feel sad/fed-up	Signposting Mental Health
I know how to deal with emotions such as anger or anxiety	Signposting Mental Health
I am comfortable with the way I look	Signposting Bullying or Mental Health
I am happy with life	Signposting Mental Health
Transfer to adult care	
I understand the meaning of 'transition' and transfer of information about me	Self-Advocacy and Transfer Explaining what transitioning is



Appendix 4: How to respond to the Steady Questionnaire

Question	Where to look if they answer no
Knowledge	
I understand the medical terms/words and procedures relevant to my condition	Glossary
I understand what each of my medications are for and their side effects	Knowledge Talking about medication and pain management or refer to prescribing clinician
I order and collect my repeat prescriptions and book my own appointments	Knowledge Talking about medication and pain management or Contacting the prosthetics services (or other medical services)
I call the hospital myself if there is a query about my condition and/or therapy	Knowledge Contacting the prosthetics services (or other medical services)
I know what each member of the medical team can do for me	Knowledge Explaining the plan for when they are an adult
I understand the differences between children’s and adult health care	Knowledge Changes from children’s services to adult services
I know about resources that offer support for young people with my condition	Knowledge or Signposting Communities groups and charities for support
Self advocacy (speaking up for yourself)	
I feel confident to be seen on my own for some/all of each clinic visit and to ask my own questions	Self Advocacy and Transfer Explaining the plan for when they are an adult and meeting the adult team
I understand my right to confidentiality	Self Advocacy and Transfer Explaining the right to confidentiality
I understand my role in shared decision making with the healthcare team e.g. Ask 3 Questions	Self Advocacy and Transfer Explaining ‘Ask 3 Questions’ and shared decision making
Health and Lifestyle	
I exercise regularly/have an active lifestyle	Health and Lifestyle Exercise and Physical Activity
I understand the risks of drugs, alcohol and smoking to my health	Health and Lifestyle Drugs, alcohol and smoking
I understand what appropriate eating means for my general health	Health and Lifestyle Diet and Eating
I am aware that my condition can affect how I develop e.g. puberty	Health and Lifestyle Development & Puberty
I know where and how I can access reliable information about sexual health	Signposting
I understand the implications of my condition and medications on pregnancy/parenting (if applicable)	Health and Lifestyle Pregnancy and Parenting

Question	Where to look if they answer no
Daily living	
I can look after myself at home in terms of dressing and bathing/showering etc	Support Pathway
I can make my own snacks/meals	Support Pathway
I know how to plan ahead for being away from home, overseas, trips, e.g. storage of medicines and vaccinations	Support Pathway
Education and your future	
I am managing at school/college (getting to and from the site, coping with work, friends and PE, for example)	Support Pathway
I know what I want to do when I leave school	Support Pathway
I have had work/volunteering experience	Support Pathway
I am aware of any potential impact of my condition to my education and/or work opportunities	Support Pathway
I know who to contact for careers advice	Support Pathway
Leisure	
I can use public transport and access my local community, e.g. shops, leisure centre, cinema	Support Pathway
I see my friends outside school/college	Support Pathway
Managing your emotions	
I know how to deal with unwelcome comments/ bullying	Signposting Bullying
I know someone I can talk to when I feel sad/fed up	Signposting Mental Health
I know how to deal with emotions such as anger or anxiety	Signposting Mental Health
I am comfortable with the way I look	Signposting Bullying or Mental Health
I am happy with life	Signposting Mental Health
Transfer to adult care	
I understand the meaning of ‘transition’	Self-Advocacy and Transfer Explaining what transitioning is
I am aware of the plan for my medical care when I am an adult	Self-Advocacy and Transfer Explaining the plan for when they are an adult and meeting the adult team
I have all of the information I need about the adult team who will be looking after me	Self-Advocacy and Transfer Explaining the plan for when they are an adult and meeting the adult team

Appendix 5: How to respond to the Go Questionnaire

Question	Where to look if they answer no
Knowledge	
I am confident in my knowledge about my condition and its management	Glossary or Knowledge
I understand what is likely to happen with my condition when I am an adult	Knowledge Talking about the impact of the condition in the future
I look after my own medication	Knowledge Talking about medication and pain management or refer to prescribing clinician
I order and collect my repeat prescriptions and book my own appointments	Knowledge Talking about medication and pain management or Contacting the prosthetics services (or other medical services)
I call the hospital myself if there is a query about my condition and/or therapy	Knowledge Contacting the prosthetics services (or other medical services)
I understand the differences between children’s and adult health care	Knowledge Changes from children’s services to adult services
I know about resources that offer support for young people with my condition	Knowledge or Signposting Communities groups and charities for support
Self advocacy (speaking up for yourself)	
I feel confident to be seen on my own in clinic	Self Advocacy and Transfer Explaining the plan for when they are an adult and meeting the adult team
I understand my right to confidentiality	Self Advocacy and Transfer Explaining the right to confidentiality
I understand my role in shared decision making with the healthcare team e.g. Ask 3 Questions	Self Advocacy and Transfer Explaining ‘Ask 3 Questions’ and shared decision making
Health and Lifestyle	
I exercise regularly/have an active lifestyle	Health and Lifestyle Exercise and Physical Activity
I understand the risks of drugs, alcohol and smoking on my condition and general health	Health and Lifestyle Drugs, alcohol and smoking
I understand what appropriate eating means for my general health	Health and Lifestyle Diet and Eating
I know where and how I can access reliable information about sexual health	Signposting
I understand the implications of my condition and medications on pregnancy/parenting (if applicable)	Health and Lifestyle Pregnancy and Parenting

Question	Where to look if they answer no
Daily living	
I am independent at home – dressing, bathing, showering, preparing meals, etc	Support Pathway
I can or am learning to drive	Support Pathway
I know how to plan ahead for being away from home, overseas, trips e.g. storage of medicines, vaccinations	Support Pathway
I understand my eligibility for benefits (if applicable)	Support Pathway
Education/Work and your future	
I have had work/volunteering experience	Support Pathway
I have a career plan (please specify)	Support Pathway
I am aware of the potential impact (if any) of my condition on my future career plans	Support Pathway
I know how and what to tell a potential employer about my condition (if applicable)	Support Pathway
I know who to contact for careers advice	Support Pathway
Leisure	
I can use public transport and access my local community, e.g. shops, leisure centre, cinema	Support Pathway
I see my friends outside school/college	Support Pathway
Managing your emotions	
I know how to deal with unwelcome comments/bullying	Signposting Bullying
I know someone I can talk to when I feel sad/fed up	Signposting Mental Health
I know how to deal with emotions such as anger or anxiety	Signposting Mental Health
I am comfortable with the way I look	Signposting Bullying or Mental Health
I am happy with life	Signposting Mental Health
Transfer to adult care	
I understand the meaning of ‘transition’ and transfer of information about me	Self-Advocacy and Transfer Explaining what transitioning is or Explaining how personal information is transferred
I know the plan for my care when I am an adult	Self-Advocacy and Transfer Explaining the plan for when they are an adult and meeting the adult team
I have all of the information I need about the adult team who will be looking after me	Self-Advocacy and Transfer Explaining the plan for when they are an adult and meeting the adult team

Appendix 6: How to respond to the Hello Questionnaire

Question	Where to look if they answer no
Knowledge	
I am confident in my knowledge about my condition and its management	Glossary or Knowledge
I understand what is likely to happen with my condition in the future	Knowledge Talking about the impact of the condition in the future
I understand what each of my medication/ treatment is for and their side effects	Knowledge Talking about medication and pain management or refer to prescribing clinician
I order and collect my repeat prescriptions and book my own appointments	Knowledge Talking about medication and pain management or Contacting the prosthetics services (or other medical services)
I know who to contact if I have any concerns about my health	Knowledge Contacting the prosthetics services (or other medical services)
I call the hospital myself if there is a query about my condition or treatment	Knowledge Contacting the prosthetics services (or other medical services)
I know about resources for young people or adults with my condition	Knowledge or Signposting Communities groups and charities for support
Self advocacy (speaking up for yourself)	
I feel confident to be seen on my own in clinic	Self Advocacy and Transfer Explaining the plan for when they are an adult and meeting the adult team
I understand my right to confidentiality	Self Advocacy and Transfer Explaining the right to confidentiality
I understand my role in shared decision making with the healthcare team e.g. Ask 3 Questions	Self Advocacy and Transfer Explaining 'Ask 3 Questions' and shared decision making
Health and Lifestyle	
I exercise regularly/have an active lifestyle	Health and Lifestyle Exercise and Physical Activity
I understand the risks of drugs, alcohol and smoking on my condition and general health	Health and Lifestyle Drugs, alcohol and smoking
I understand what appropriate eating means for my general health	Health and Lifestyle Diet and Eating
I am aware that my condition can affect how I feel and function e.g fatigue, sexual function, fertility	Health and Lifestyle Function & Feeling or Signposting
I know where and how I can access providers for accurate information about sexual health	Signposting
I understand the implications of my condition and drugs on pregnancy/parenting	Health and Lifestyle Pregnancy & Parenting

Question	Where to look if they answer no
Daily living	
I am independent at home – dressing, bathing, preparing meals etc	Support Pathway
I can or am learning to drive	Support Pathway
I know how to plan ahead for being away from home, overseas, trips e.g. storage of medicines, vaccinations	Support Pathway
I understand my eligibility for benefits (if applicable)	Support Pathway
College, Work and your future	
I am managing at college/work e.g getting to and around, nature of work, friends etc	Support Pathway
I have had experience of working/volunteering	Support Pathway
I have a career plan (please specify)	Support Pathway
I am aware of the potential impact (if any) of my condition on my future career plans	Support Pathway
I know how and what to tell a potential employer about my condition (if applicable)	Support Pathway
I know who to contact for careers advice	Support Pathway
Leisure	
I can use public transport and access my local community, e.g. shops, leisure centre, cinema	Support Pathway
I have friends and see them socially	Support Pathway
Managing your emotions	
I feel confident in telling people about my condition e.g. friends, family, employers	Signposting Community groups and charities for support
I know someone I can talk to when I feel sad/fed up	Signposting Mental Health
I know how to cope with emotions such as anger or anxiety	Signposting Mental Health
I would like more information about where I can get help to deal with my emotions	Signposting Mental Health
I am comfortable with the way I look to others	Signposting Bullying or Mental Health
I am happy with life	Signposting Mental Health



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