PreAmp conversations: Staff Checklist

DE MONTFORT UNIVERSITY LEICESTER

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01 Introduction

This checklist has been developed through a process of co-design research aimed at improving the resources and support for preparing patients psychologically for amputation surgery. Both patients and staff have had equal input into this resource through the underpinning research and co-design process.

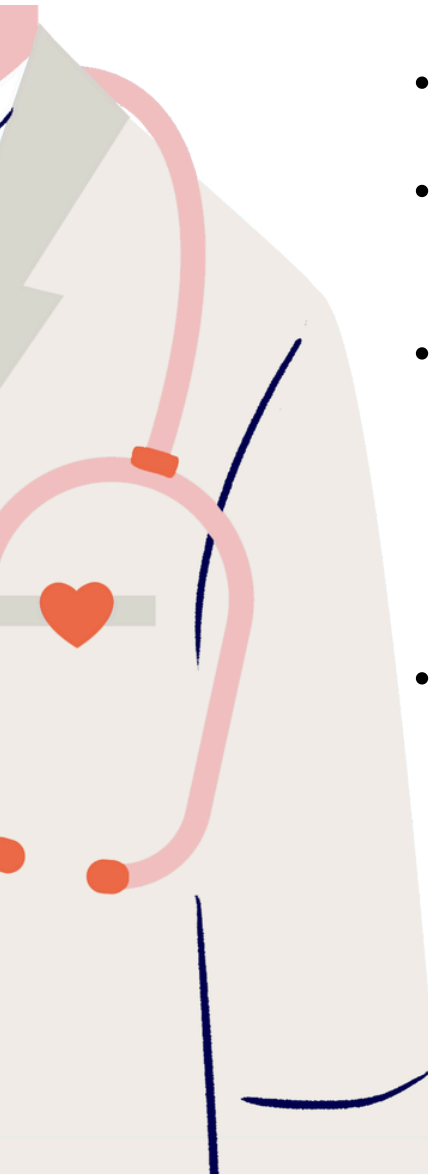
This checklist outlines key domains that may be relevant to discuss with patients pre-operatively in order to help patients to prepare for their amputation surgery. It is not an exhaustive list, and is intended to complement existing pathways regarding physical preparation for surgery. One of the core aspects of the underpinning research is that preparation is everyone's responsibility in the clinical setting and provision of a more 'standardised' approach towards this may help with ensuring staff feel empowered to do this work and that patients get similar opportunities for preparation conversations.

This guide to support the checklist is provided as an educational/ training resource which may be helpful for new starters in your organisation, and to help scaffold the items included on the conversation checklist itself.

Compassionate conversations

02

Amputation surgery is likely to be life altering for most patients- "…it's not an appendix which you recover from and then in a month you're forgetting about it. It's something which is permanently life changing" (Staff Participant in the PreAmp study). Discussing the need for, and process and outcomes of an amputation is likely to invoke a range of emotions for patients. Framing these discussions as 'compassionate conversations' as opposed to 'difficult' or 'challenging' conversations may be a helpful strategy. Compassionate conservations involve:

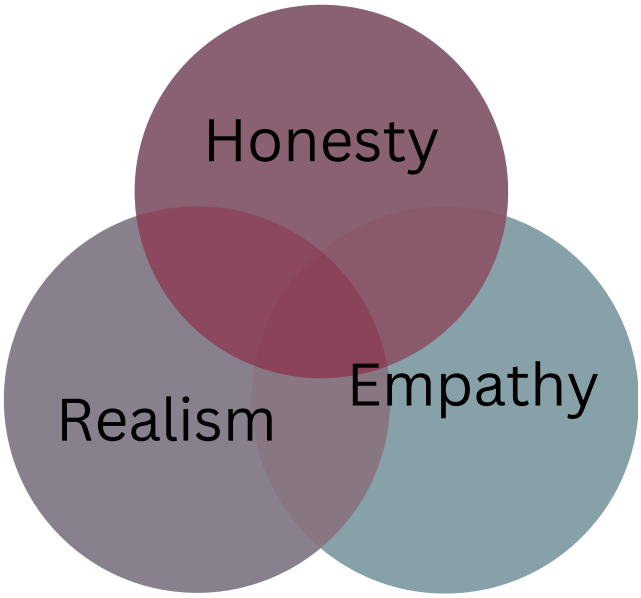


- beginning all discussions with the intention that it will be meaningful and helpful dialogue,
- they prioritise active listening- hearing the other persons views is central- aim to 'listen to understand' rather than 'listen to respond'
- connecting with the other conversant as a human being. Discussing amputation surgery may be routine for clinical staff, but for patients the discussion with them about their amputation surgery may be the first time they have ever thought about or imagined life as an amputee.
- suspension of judgement or assumptions- being open minded to the specific interactional context you are in is important and making sure you haven't assumed understanding or knowledge but rather been open and inclusive in the exchange

Core values for preparation conversations

03

From our research, healthcare professionals routinely identified the following values as important for good pre-operative preparation conversations:



Patient's value "Explanation, reassurance and knowing I was in safe hands" (Patient Interview – PreAmp study) which aligns closely to the above values demonstrates what a well- prepared patient might be; well informed, confident in their care team and emotionally supported.

- Consent should include the whole process
- Patients need to know the outlook for them, including expectations for them in the short, medium and longer term
- Risks should be conveyed- even when these are around difficult topics – but hope is also needed within this

04

Experience of conducting preparation conversations

Item ** which precedes the core items of the checklist, may not be relevant to all staff members using the checklist. For those new to their roles or the organisation, they may wish to consider if they would find it helpful to observe an established/ experienced colleague (this should be someone who is used to conducting compassionate conversations around the topics on the checklist) conducting a pre-operative preparation conservation with a patient as a training and development activity. Those wishing to improve their own practice may also wish to consider if such observation would be helpful to them. Peer observation and feedback is often found to be a helpful way of improving and developing practice in a safe and meaningful way. Everyone will approach conversations in their own personal style, but observation allows you to consider what was effective and how you could assimilate elements into your own practice.

Staff report that aspects of the pre-operative discussions involve emotionally challenging topics and being able to approach such conversations effectively requires confidence, both in the information to be discussed and the manner in which to do it. Observation of others to build skills may be an effective way for building such confidence. Item ** may not be applicable each time a preparation conversation takes place, but it is included as a stop-check so that staff can feel comfortable to acknowledge they want to develop their skills further. Good preparation conversations will undoubtedly benefit patients so having a built-in mechanism to consider development of skills in this domain is hopefully useful.

05

Context of checklist items

Item 1: Patients understandings of amputation

A clarity of plan is seen as helpful for preparing patients. Professionals routinely note that patients understanding what is happening is a key means of assessing their preparedness for surgery and that knowing what is going to happen helps patients post-operatively. Lots of patients talk about being unclear about what is going to happen and why and this creates confusion and anxiety for them. Due to shock, medication, pain patients often identify that they do not take in everything that is said to them during consultations or ward rounds. Asking patients to explain back to you what they understand about what surgery they are having and what will happen is a good way of assessing what knowledge gaps they have to help them prepare for the surgery ahead. Patients in the PreAmp study told how important it was to understand why they were having the surgery, e.g., if there was a risk to their life in not having it done, made it easier for some patients to assimilate that they needed the surgery doing. If patients are not clear on what is going to be happening, then providing additional information and opportunities for them to ask and have questions answered may be important.

Item 2: Family and Friend involvement

A patient in our study noted that "...your friends, family and that are sitting at home worried and they've got nobody [to support them]". Family and friends should be included in conversations where possible and should know who to ask to questions to on the ward. The Vascular Society GB&I Best Practice Clinical Care Pathway for Major Limb Amputation states that care decisions in the pre-operative phase should be made in conjunction with the patient and their family. The inclusion of family and/or friends (where most appropriate) may help in the preparation for amputation surgery. Family and friends are themselves often unsure of what life will be like for their family member/friend post-amputation, so inclusion can help them understand the patient journey but also to help them prepare for their own role as a carer or supporter of the amputee. The challenge of conversations primarily happening during ward rounds may be prohibitive to family and friend inclusion but creating potential opportunities with members of the care team to talk with family and friends during visiting hours may be beneficial for patients and their supporters. Provision of the FAQ document to Family and friends may also be helpful, as well as signposting to the patient story videos that PreAmp have created. It is also possible for family/friends to refer themselves to the Limbless Association for peer support through their Volunteer Visitor scheme.

Context of checklist items

Item 3: Risk conveyance

The risks of any surgery are an important part of the consent process and pre-operative discussions, but for the prospective amputee, ensuring that the range of risks is discussed is seen to be important. Whilst the discussion of risks around mortality and life post-operatively (wound healing, likely functional outcomes) are likely challenging topics, they are important to address to ensure patients are well informed about what to expect after surgery. A very strong thread of our research was the importance of realistic and honest discussions of expectations with patients. Over promising patients can lead to disappointment and distress. Risk, as with any risk assessment, should be considered in terms of the likelihood but also the strategies that will be used to mitigate said risk. Such an approach allows for the weighing up of the balance of probabilities but also enables such discussions to offer hope, whilst remaining realistic about the journey ahead for the prospective amputee. Whilst predicting outcomes in the long term can be challenging, its important to give patients sufficient information beyond just the short term, e.g., the immediate surgery, and ensuring they understand the road ahead as phases of their treatment and recovery and the risks within that may be helpful for enabling them to prepare psychologically for what is ahead.

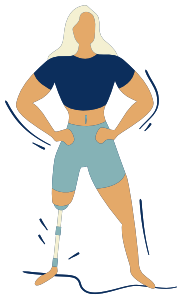
Item 4: Emotions

The need for amputation surgery is likely to provoke a range of emotions for patients. It is important to be mindful that clinical needs and emotional needs may be different during this time. The most common emotions and emotional reactions patients might experience during this time are:

- Fear
- Shock
- Grief
- Anxiety
- Denial
- Distress
- Overwhelm/ stress

Context of checklist items

These emotions may impact the ability of patients to take in information- particularly if they are shocked and overwhelmed. Evidence suggests that the loss of a limb is akin to the level of grief experienced when losing a spouse. The grief experienced should therefore not be underestimated. From our research, patients need those feelings validating; its not about 'solving' those uncomfortable emotions, but acknowledgement that they are normal and providing additional support to help with them where needed. Patients may need permission to grieve, normalisation of the loss and change may help with that. Peer support with other amputees may help with the normalisation of these feelings, evidence shows connection with others who share a similar lived experience can be beneficial. The Amputee charity- Finding Your Feet- has a range of videos about emotions and mental health which some patients may find useful to engage with.

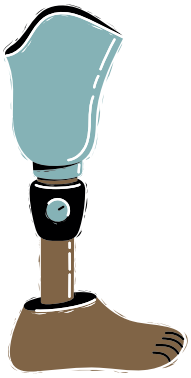


Item 5: Disposal of the amputate

The Human Tissue Authority (HTA) states that "the disposal of human tissue should be managed sensitively and the method of disposal should be appropriate to the nature of the material;". Dignity is one of the core guiding principles of the HTA. Some patients may 'wonder' about their amputated limb, including how it was disposed of. The grieving for the limb may be exacerbated by the lack of knowledge about how their limb was disposed of. Providing information on disposal may be important for some patients, it should not be assumed that only patients with specific religious beliefs will be curious to know about the manner of disposal of the amputated limb. Some patients will have other non-religious beliefs or preferences around the disposal of their limb. Standard procedure is for amputated limbs to be classified as clinical waste and then be incinerated via waste management processes. Some hospitals have other bespoke/local processes for limb repatriation should the patient wish. Whilst individual cremation is not legally permissible, it may be possible for patients to arrange burial of their limb, or repatriation of it to their funeral director for storage for those who wish to be buried or cremated with their amputated limb at a later stage

Context of checklist items

Disposal of the limb should be discussed with patients, checking if they wish to know first. A simple explanation around clinical waste disposal and emphasis on this being appropriate and sensitive to the limb is likely sufficient. Questions around disposal should be encouraged ahead of surgery as post-operatively waste management processes may have been completed and any wishes of the patients may not be able to be facilitated. For patients with religious beliefs who have concerns around clinical waste incineration, encouraging them to speak with their community religious leader or chaplain would be advisable to allay any concerns they have. Patients indicate they prefer personal language in such conversations, e.g. 'Your leg' or 'your limb' and avoiding calling it 'waste' is sensitive to the significance of the loss for patients.



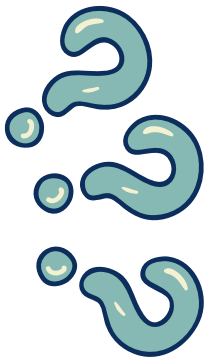
Item 6: Helping the patient prepare for their residual limb

Patients are often highly curious about what their residual limb will look like and what the healing process may be. Patients may feel shy to ask about what the appearance of the wound and residual limb will be. Not all patients who are undergoing an amputation will have seen an amputee before their own surgery, so may not have a clear idea of what their residual limb(s) may look like after surgery. Consideration of whether use of stock images of a healed residual limb for amputated digits, AKA/ BKA and upper limbs might be useful to help patients visualise how their bodies may look (mindful of variations between patients and bodies). Helping patients to understand the change to their body and body image may help with their subsequent adjustment. Specific focus on explanation of the healing process and approximate timescales may help patients to understand the medium to longer term healing. Explaining when dressings will be changed post-operatively and when patients will be able to see the residual limb may also help with patients' uncertainty about how their body will look immediately after the operation.

Context of checklist items

Item 7: Questions

Asking, and having questions answered, is a vital means for patients to understand the specifics of their own care and to have their concerns or fears about surgery allayed. In line with the notion of compassionate conversations, using the phasing of 'what questions do you have?' rather than 'do you have any questions?' has been found to elicit more responses as it assumes people will have questions at the outset. Patients may be unsure about what to ask and whether it is appropriate, and may often need time to consider their questions and then ask them later. Considering what mechanisms you can use to allow that to happen is likely helpful. For example, making sure the patient knows they can ask any member of staff on the ward a question, or ensuring that the relevant professional can be found for them if it's a specific question for one area. Signposting to peer support may also be helpful for patients being able to ask questions about life as an amputee, so that they can get the insights of someone who has been through the same experience. Patients can self- refer to the Limbless Association Volunteer Visitor scheme or there is a clinical referral route if they prefer you to facilitate that for them. Providing patients with the PreAmp Frequently Asked Questions (FAQs) document may also help with answering common questions and it also includes a list of questions that patients may want to ask their care team which has been devised from the research with patients and clinical staff.



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