

Amputee & Trauma Support Group UK

The best medication is communication

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Charity Registration No. 1193016



“

Enable the disability,
translate disability
into ability; capability,
a winning opportunity
- indeed a Reality

”

ATSGUK welcome booklet

HELP DESK

Information to navigate the journey ahead.

SIGN POSTING

Visit our website for sign posting to support you and your family.

DEDICATED TO BE BY YOUR SIDE

We can visit you whilst you are in hospital on the ward or at home utilising our volunteers experience of trauma.

COMMUNICATING AND COMMUNITY

 Join our facebook community.
Coffee mornings, events for all.



www.atsguk.co.uk



Amputee and Trauma Support Group UK (“ATSGUK”) have put together a welcome pack to help guide you through your new journey following your traumatic injury or amputation.

Our dedicated team who have themselves experienced a life changing traumatic event are here for you to answer any questions you may have.

Let’s get started.

What Will I Feel After A Traumatic Event?

Immediately After

Immediately after a traumatic event it is common for people to feel shocked, or numb, or unable to accept what has happened.

Shock - when in shock you feel:

- stunned or dazed or numb.
- cut off from your feelings, or from what is going on around you.

Denial - when in denial, you can’t accept that it has happened, so you behave as though it hasn’t. Other people may think that you are being strong or that you don’t care about what has happened.

Over several hours or days, the feelings of shock and denial gradually fade, and other thoughts and feelings take their place.

What Happens Next?

People react differently and take different amounts of time to come to terms with what has happened. Even so, you may be surprised by the strength of your feelings. It is normal to experience a mix of feelings. You may feel:

- **Frightened** ... that the same thing will happen again, or that you might lose control of your feelings and break down.
- **Helpless** ... that something really bad happened and you could do nothing about it. You feel helpless, vulnerable and overwhelmed.
- **Angry** ... about what has happened and with whoever was responsible.
- **Guilty** ... that you have survived when others have suffered or died. You may feel that you could have done something to prevent it.
- **Sad** ... particularly if people were injured or killed, especially someone you knew.
- **Ashamed or embarrassed** ... that you have these strong feelings you can’t control, especially if you need others to support you.

- **Relieved** ... that the danger is over and that the danger has gone.
- **Hopeful** ... that your life will return to normal. People can start to feel more positive about things quite soon after a trauma.

What Else Might I Notice?

Strong feelings affect your physical health. In the weeks after a trauma, you may find that you:

- cannot sleep
- feel very tired
- dream a lot and have nightmares
- have poor concentration
- have memory problems
- have difficulty thinking clearly
- suffer from headaches
- experience changes in appetite
- experience changes in sex-drive or libido
- have aches and pains
- feel that your heart is beating faster

What Should I Do?

- **Give yourself time**
It takes time, weeks or even months to accept what has happened and to learn to live with it. You may need to grieve for what (or who) you have lost.
- **Find out what happened**
It is better to face the reality of what happened rather than wondering about what might have happened.
- **Be involved with other survivors**
If you go to funerals or memorial services, this may help you to come to terms with what has happened. It can help to spend time with others who have been through the same experience as you.
- **Ask for support**
It can be a relief to talk about what happened. You may need to ask your friends and family for the time to do this and at first they will probably not know what to say or do.
- **Take some time for yourself**
At times you may want to be alone or just with those close to you.
- **Talk it over**
Bit by bit, let yourself think about the trauma and talk about it with others. Don't worry if you cry when you talk, it's natural and usually helpful. Take things at a pace that you feel comfortable with.

- **Get into a routine**
Even if you don't feel much like eating, try to have regular meals and to eat a balanced diet. Taking some exercise can help, but start gently.
- **Do some 'normal' things with other people**
Sometimes you will want to be with other people, but not to talk about what has happened. This can also be part of the healing process.
- **Take care**
After a trauma, people are more likely to have accidents. Be careful around the home and when you are driving.

What Should I Not Do?

- **Don't bottle up your feelings**
Strong feelings are natural. Don't feel embarrassed about them. Bottling them up can make you feel worse and can damage your health. Let yourself talk about what has happened and how you feel and don't worry if you cry.
- **Don't take on too much**
Being active can take your mind off what has happened, but you need time to think to go over what happened so you can come to terms with it. Take some time to get back to your old routine.
- **Don't drink or use drugs**
Alcohol or drugs can blot out painful memories for a while, but they will stop you from coming to terms with what has happened. They can also cause depression and other health problems.
- **Don't make any major life changes**
Try to put off any big decisions. Your judgement may not be at its best and you may make choices you later regret. Take advice from people you trust.

How Can I Help Someone Who Has Experienced A Traumatic Event?

- **Be there**
It can be helpful just to spend time with someone, even if they don't want to talk about what happened. Let them know you are available to listen and offer to visit again.
- **Listen**
They may find it helpful to talk about what happened. Don't pressure them - let them take things at their own pace.
- **Offer practical help**
They may find it more of a struggle to look after themselves and keep to a daily routine. Offer some help, such as cleaning or preparing a meal.

Your Doctors Team

Your treating doctors are there to help you from the start of your journey to navigate the health care system and with help from their team they will start organising and arranging a professional team of experts to help with your recovery process.

As you are contacted by each department it is useful to write down which you found helped more with your recovery, what questions you need answering and the plan moving forward.

Feel free to use the welcome pack to store contact information and treatment dates. In the experience of the volunteers at ATSGUK if your family is involved from the outset and you all work as a team, you can overcome the challenges ahead.

Your Team

Doctors and Consultants

Ward Staff and Nurses

Pain Management Experts

Medication

Ensure that all your medication is all up to date for any pre-existing medical conditions and everybody knows what you are taking and what dosages. You may find it useful to always carry a medication list in your wallet or purse or keep a copy on your smartphone.

Physiotherapy

Physiotherapy is key and this may start whilst you are in hospital or you may be allocated to a physiotherapy team post discharge for intensive treatment. It can be hard work, but this is the start of your new life. It is always helpful to ask your physiotherapist for leaflets and guidance on exercises that you can do safely at home to help you gain more independence and fitness.

Occupational Therapy

Occupational therapy is also a very important part of your rehabilitation. Make sure if possible you request a home visit so that the occupational therapist who assesses you can see first hand where you live, what adaptations to the home you require to make it safe, as well as helping you gain greater independence.

Adaptations To Your Home

If you are housed by the local council make sure a copy of the occupational therapist's report is sent to the council. If you are in private housing as either a

tenant or an owner occupier, please do not hesitate to contact Mark Riddington or Beverley Riddington at ATSGUK as they have experienced all the ups and down working previously within the disability adaptations industry. They can help answer any questions you have and help you navigate the complicated system.

Your General Practitioner

Make sure your GP is fully up to date with the plans for your treatment following your traumatic injury, the medications you are now on, your physiotherapy and other hospital appointments, hospital transport arrangements and visits organised by others at home for district nurses and carers.

Prosthetic Clinic Appointments

Once you are at the Prosthetic Clinic then this is where your journey to true independence really begins.

Make sure you take on board all the processes, ask questions, discuss the goals you want to achieve and information is key. Work with your prosthetic clinic and make sure they are fully aware of any issues or problems you have with your prosthetic and albeit they are the professionals, you are the limb wearer, so it's down to you to let them know how the limb fits.

Family

Family is so important and discuss all your concerns and work together with them to help you have an emotional support system. If your partner or other family members have questions again ATSGUK are here to answer their questions and available at the end of the phone for you and for them.

What To Expect Following An Amputation

Having an amputation is a life changing event and you will need to adapt to a new normal.

The recovery process is different for each individual depending on your general health and fitness, your frame of mind, pain management, where you will be living and the support you receive.

Goals

These can be small everyday milestones to achieve on your way to bigger and more ambitious goals that you wish to pursue in the future.

Goals are important as a motivational tool and help focus the mind and gives you positive attitude. It will also help with the healing process and your overall mental wellbeing.

At ATSGUK we offer a free 'mentoring service' for you to use where one of our amputee volunteers, who themselves have been on the journey to living a full and active life following an amputation many years ago, can advise, inspire and motivate you along your own journey.

Diary Record

A diary is a must and we advise that you keep a daily log to include things such as how did you sleep, your pain levels, what you can and can't do so that at the end of each week you can highlight what is concerning you to feedback to your health professionals who are treating you or you can contact our volunteers at ATSGUK for help and guidance.

Mental Health

At ATSGUK we strongly believe that the best medication is communication. Beverley Riddington at ATSGUK who is a wife of an amputee and a qualified psychological counsellor can be contacted via the charity to advise you on how to cope with certain situations and how to approach the situation of mental health following an amputation.

An amputation can feel like a bereavement and coming to terms with losing a limb can be hard to come to terms with. Some people suffer early on in their journey following an amputation, whilst others can suffer throughout their life. At ATSGUK our volunteers have experienced an amputation themselves and the charity's facebook group is a great place to ask questions and get some helpful answers.

Driving

Mark Riddington at ATSGUK is as a double above the knee amputee and he is now back driving a car using hand controls. This has given him independence and opened opportunities to him which otherwise he could not access if he was unable to drive.

The first thing to do is to contact your local DVLA office and inform them of your disability. They will then send out some forms for you and your GP to sign and return to them and thereafter, you need to apply for a Blue Badge.

It is useful to also enquire about 'Mobility Schemes' through which you may be entitled to a specially adapted car e.g. with hand controls and they can also arrange driving lessons for you to master the new controls.

Recreation and Sports

What ever your level of mobility, recreational activities based on you as an individual can help with circulation, pain management, fitness levels and your overall mental wellbeing.

Ask yourself what did you do before your amputation and how can that sport or recreational activity be adapted to your disability to enable you to resume running, play football, going cycling etc.

Check out your local disability groups and local sporting venues for what disability sporting activities they promote. It is not only a great way to start sporting activity, but it gets you involved with like minded people who have suffered similar injuries to you.

Falls

We need to discuss this as all amputees will experience this along their journey following an amputation.

A safe place is a happy place so between you, your family, the occupational therapist and your physiotherapist make sure you cover all the bases.

Many amputees find that whilst getting rehabilitation early on after an amputation at hospital, they often fall and learn techniques to get up and try again.

Make sure whenever you are out and about by yourself you carry a phone and make sure you inform someone responsible where you are going to be.

Phantom Pain

Managing Phantom Pain

Phantom Limb Pain (“PLP”) refers to on going painful sensations that seem to be coming from the part of the limb that is no longer there. The limb has gone, but the pain is real.

The onset of this pain most often occurs soon after surgery. It can feel like a variety of things, such as burning, twisting, itching or pressure. It is often felt in fingers or toes. It is believed that nearly 80% of the amputee population worldwide has experienced this kind of pain.

The length of time this pain lasts differs from person to person. It can last from seconds to minutes, to hours, to days. For most people, PLP diminishes in both frequency and duration during the first six months, but many continue to experience some level of these sensations for years.

People are often reluctant to tell anyone that they are experiencing PLP or phantom limb sensations, for fear that they will be considered “crazy.” However, it is important to report these pains as soon as you begin to experience them so treatment can be started.

What Causes Phantom Limb Pain?

Unlike pain that is caused by trauma directly to a limb, PLP is thought to be caused by mixed signals from your brain or spinal cord. This is an important concept to consider, because the treatment for this pain has differences from the treatment you would

receive for other kinds of pain. New therapies for PLP all involve trying to change the signals from your brain or spinal cord.

As with any other kind of pain, you may find that certain activities or conditions will trigger PLP. Some of these triggers might include:

- Touch
- Urination or defecation
- Sexual intercourse
- Angina
- Cigarette smoking
- Changes in barometric pressure
- Herpes zoster
- Exposure to cold.

If you notice any particular thing triggering an episode of PLP for you, let your healthcare provider know. Some triggers can be avoided, for example, you can prevent constipation or stop smoking. For other triggers, you will just have to understand and treat accordingly. You will not be able to prevent the barometric pressure from changing, but you will be able to understand that your PLP might be more severe on days with big shifts in the weather.

Treating Phantom Limb Pain

Treating PLP effectively takes a multipronged approach. Medications of several different categories in combination with non-medication treatments seem to be most effective. This combination of medication and non-medication is similar to treating other painful conditions.

For instance, if you broke your leg, you would expect to take narcotic pain medication, at least for a while. You would also elevate your leg and put ice on it.

For PLP pain management, you will take medications directed specifically towards interrupting the pain signals in your brain or spinal cord, as well as using certain non-medication therapies, which also work on your brain's interpretation of these signals.

Medications For Phantom Limb Pain

There are many different categories of medications that can decrease your pain. Each of them is thought to work on different kinds of pain sensations. The categories of some of the medications you might be given include:

- Acetaminophen and non-steroidal anti-inflammatory drugs (NSAIDs)
- Opioids (narcotic pain medications)
- Antidepressants
- Anticonvulsants

- Beta-blockers
- Muscle relaxants.

Some of these medications work best if taken in combination with other medications and if given at certain times of the day. The antidepressants typically used work best if given at bedtime, and are often taken at the same time as the anticonvulsants. Finding the right medications with the fewest side effects will require you and your healthcare provider to work closely together.

Non-Medication Treatments For Phantom Limb Pain

Alternative or complementary therapies can be helpful for the reduction of PLP. These include:

- Acupuncture
- Massage of the residual limb
- Use of a shrinker
- Repositioning of the residual limb by propping on a pillow or cushion
- Mirror box therapy
- Biofeedback
- TENS (Transcutaneous Electrical Nerve Stimulation)
- Virtual reality therapy
- Imagery
- Music

What You Need to Remember

- Phantom limb pain and sensation is common for most people after amputation surgery. Symptoms generally improve over time.
- Your phantom limb pain and sensation can be managed so that it does not overwhelm your life.
- The goal of pain management is to reduce pain levels to allow you to get back to living and enjoying life again.
- Work closely with your healthcare team to create and maintain the pain management plan that works for you.
- When possible, avoid things that trigger your phantom limb pain and sensation

ATSGUK is here to help you and can provide support and advice to guide you in the right direction.



ATSGUK CONTACTS

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Charity Registration No. 1193016



hospital ward visits or home visits



our community
is here to inspire, motivate & communicate



disability is ability

ATSGUK understand from life experiences that a traumatic event can be devastating and can definitely cause a significant change to many aspects of your life and impact on your family circle. You are not alone, let us be the foundation to rebuild your life.



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