Somerville Heart Foundation
For young people and adults born with a heart condition

Preparing for and Coping with Surgery

Going for surgery can make you feel lots of difficult emotions. It is normal to feel anxious, frightened, down, angry and upset. Fear and anxiety are the body's normal response to a threat. Even when you understand that you need surgery to survive, it is difficult to override the body's instinctive response to being hurt. However, understanding why you feel like this and learning how to better manage these feelings can make this difficult time a little easier.

You might also feel powerless. If you feel that you have no control over a situation then in addition to anxiety, often you can feel down. The nature of the doctor/nurse - patient relationship can also lead to you feeling disempowered and therefore as if you do not having a say about what is happening. Various strategies can help you to cope with these difficult emotions and feel more in control of what is happening to you.

Gaining control and asking questions

If you have any particular questions then you have the right to ask these of your medical team. It is your body and you have the right to know as much as you feel comfortable with. Often it can feel overwhelming talking to doctors, so it is a good idea to write your questions down so that you don't forget them. Don't worry about appearing silly it is okay to ask for things to be explained clearly. Ask them to draw a diagram if that would help you to understand.

- Find out what time your surgery will happen, how long it will take and the likely recovery time needed so that you can prepare yourself and make plans for recovery.
- Find out what is likely to happen when you come round from the anaesthetic. Will you be kept in the recovery room? Will you be going to an Intensive care ward or the routine cardiac ward? Will you be attached to a ventilator, drip or catheter? You can feel disorientated after surgery and it will help if you can make sense of where you are and what is going on.
- What is likely to be the impact of surgery on your body for example, do bones need to be broken? How long will it take to heal?
- If you are worried about pain ask how this will be managed.
- If anaesthetic usually makes you sick then you can be given medication before surgery to stop this from happening. Discuss this with the anaesthetist beforehand.

- If you have concerns about scars ask about this. It takes time to come to terms with a new scar but this process is easier if you are prepared and know what to expect.
- If you want to know then ask about the risks involved. This way you can prepare yourself for any realistic outcome. Often when we don't know the facts it is easier to imagine the worst.
- Think about whether you would like to make a living will and organise this with a lawyer beforehand.
- You have a right to privacy in hospital just like you do in any other walk of life. Make sure that staff respect this right by using bed screens and giving you the opportunity to use bed baths or commodes in private. If you need help getting dressed this should be done with discretion and respect.
- If you have any worries or concerns throughout your hospital stay then speak to a doctor or a nurse about them. You know your body better than anyone and your concerns should always be heard. If you do not understand what is happening to you then ask. If you are not satisfied with the answer then ask to speak to someone else. Be polite and reasonable but assertive (it is easy to become frustrated and angry but this won't get you the reaction that you want).

Coping with Difficult Emotions.

Different people find different helpful strategies for managing emotions. It is helpful to build up some tools that you can use when you are feeling overwhelmed. Here are some suggestions. Try different things out until you find what works for you.

Breathing exercises: Relaxation starts with your breathing. When we are anxious we hyperventilate and take shallow quick breaths which further drive feelings of anxiety. Focusing on breathing from your abdomen can help you to calm down. Put your hand on your tummy and try and breathe so your tummy moves in and out.

Meditation and relaxation are powerful tools for managing pain and anxiety. You could take some relaxation tracks on an iPod or music player to listen to. Different people find different kinds of meditation helpful. Explore different techniques such as visual imagery, Mindfulness, breathing exercises, progressive muscular relaxation or self hypnosis and use what works for you.

When we are anxious or in pain we hold tension in our body. Scan your body to feel where you are holding tension (often the shoulders) and try to relax this area.

Alternative therapies such as using a relaxing temple balm with lavender oils can aid relaxation.

Distraction is another helpful tool for both relaxation and managing pain. Tasks that focus attention without requiring too much thought are good for distracting an agitated mind. Repetitive tasks such as playing simple card games like Patience or Snap or puzzles such as Suduko or a Crossword might help. Other ways to distract yourself include watching a favourite DVD, listening to music or chatting to loved ones.

Another technique that can help is to imagine yourself running. The normal reaction in a threatening situation is to fight the threat or to escape but in hospital you have to suppress these desires and force yourself to undergo painful procedures. Imagining yourself running to safety can help.

EFT (Emotional Freedom Technique) is an effective self tapping technique that helps to process difficult emotions quickly. Learning how to do this can help you in stressful situations such as waiting for surgery.

Talk to someone about how you are feeling instead of bottling everything up. This might be to a close friend, family or to a sympathetic nurse or if available a counsellor. It is okay to cry, have a bit of a rant and get all of your feelings out. If you don't feel like talking to anyone about how you are feeling it might help to write it down in a diary or notebook instead.

Remember people don't always say the right thing. It is hard for people to get it right especially when they have not been through the same experience. Common misunderstandings include thinking it is somehow easier for us to cope with surgery and ill health because "we are used to it" when in reality it is more difficult for this very

reason. Instead of being frustrated by such remarks try and explain what you actually feel.

Acknowledge feelings: You might also feel angry that you have to go through this. Again this is normal. It is okay to acknowledge that it is not fair that you need surgery and that you were born with a heart condition. It is important to find a healthy way to express this anger rather than further punishing yourself and your loved ones with unhealthy coping strategies.

One of the things that makes surgery and being in hospital sometimes more difficult for people with congenital conditions is all of the reminders of previous difficult experiences in hospital. It is difficult and quite unusual to have to face the same potentially traumatising experience again and again. That is why it is so important to find ways to make this as bearable as possible and to look after yourself. Remember, as an adult you have more control about what is happening to you than you may have had as a child.

If you find that you are not getting the support that you need from those around you then rather than pushing loved ones away or bottling everything up seek this support elsewhere, for example, from others who have had similar experiences.

The night before surgery you might be offered a sleeping pill and on the day you might be offered a PreMed which is usually made up of sedatives to try and help you feel calmer before going to theatre. It is up to you if you want to take these.

Self Care in Hospital

Being in hospital and going for surgery is a difficult and stressful time. Look after yourself as much as possible. Little things can make a big difference:

Before going into hospital pack a bag with all of the ‘tools’ that can help you get through this difficult experience. Take things that make you feel better including photographs of loved ones and happier times, music that you find comforting, comfortable nightwear (PJs that button up are easier to take on and off since after cardiac surgery it can be painful to lift your arms up to put a top over your head), body cream that you like the smell of, a small handheld fan, games to play, a good book, your favourite sweets and a new “going home” outfit.

Go easy on yourself. Appreciate that this is a difficult experience and that it is understandable if you get upset at times or feel anxious, angry or down. This does not mean that you are not coping just that you are a normal human being who is reacting to exceptionally difficult circumstances with normal emotions.

Initial recovery post surgery

Focusing on recovery and the hope of getting better is what gets us through surgery and hospitalisation. The length of time it takes to recover from surgery obviously depends on the procedure involved but some general points may help:

Initially you will probably feel very sleepy. You will also probably feel in pain and quite unwell. Taking things each moment at a time is effort enough.

Ask for anything that might make you feel a bit more comfortable, for example, an extra pillow, a fan, a cool compress on your forehead, some ice cubes on your lips (if you are still nil by mouth you might be allowed this) or help moving into a more comfortable position.

If you don't feel up to visitors then explain this to them and kindly ask them to come back later or the following day. It is difficult for "well" people to understand just how unwell you feel. It can be exhausting to even just listen to people talking around your bed.

Sleep is how the body recovers but this is not always easy on a busy cardiac ward between bleeping heart monitors, nurses taking your ob's, doctor's rounds and requests for ECGs and X-rays. Meals are usually at set times and you might be woken up for breakfast or for your bed to be changed. Try and work around this to get as much rest as you need while being assertive about how much disruption you can tolerate (e.g. if you don't want to be woken up for breakfast ask for a note to be hung on your bed stating this).

Once you start to feel a little better it can help you to set goals. For example, eating your first food, being able to sit up in bed, getting to stand, and going for a little walk are all significant achievements. Eventually drips will be removed and then your stitches and you will get to change into your clothes and go home. Remember there might be setbacks along the way and always pace yourself by listening to your body. 5

"Congenital heart disease survivors pay a price to live. Often one such cost is enduring surgery. I have experienced over 14 surgical procedures to date including Open Heart Surgery. I was born with an Atrial Septal Defect and Complete Heart Block and I am completely dependent on a pacemaker.

This means that I will always require further surgery to replace my pacemaker and over time this has involved further complications caused by the number of pacemakers and pacing wires that I have been fitted with over the years.

I have always considered surgery to be like a marathon (although I have never actually run in one!). I focus all of my energy and determination on getting through the procedure and on recovering, setting myself goals along the journey. Of course this is never easy and at times when things have gone wrong and I have found myself back in theatre I have wondered if this is a price worth paying. But then my survival instinct kicks in and I know that it is.

Sometimes I get angry about my lot in life but I know that there is nothing that I or anyone else can do about the fact that I depend on surgery and a pacemaker to live. So I focus on what I can do to make this situation as easy as possible and on living well in the time I have between hospital stays."

- Don't suffer in silence, report any unmanageable pain or discomfort. You can also use relaxation and meditation techniques to manage pain.
- Accept help. You have got through what most people have not and the consequences of being born with a heart condition reach far beyond the physical symptoms.
- Eat well. Your body has been through an ordeal. It will take time to build yourself back up. It might help to take supplements or a tonic.
- It may be that you can now do more that you could before your hospital stay or it might be that you cannot do as much. Either way requires an adjustment to how you see your body especially if you are left with a new scar or have been fitted with a cardiac device such as a pacemaker. If you have any loss of functioning it is okay to grieve and process this loss.
- Pace yourself. Of course you want to get better and back to your "normal" self but appreciate what you have been through and give yourself time to heal physically and emotionally.
- Plan treats for yourself for when surgery is over and you feel up to it.
- Before and after hospitalization it can help to prepare the body with healing techniques such as Reiki, Acupuncture, Reflexology or Indian Head Massage.
- Set goals for when surgery is over. Visualise yourself achieving these goals.

Further Resources:

World of Relaxation: A Guided Mindfulness Meditation Practice for Healing In the Hospital And/or At Home by Jon Kabat Zinn.

Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness by Jon Kabat-Zinn.

The Open Heart Companion: Preparation and Guidance for Open-Heart Surgery Recovery by Maggie Lichtenberg, PCC

The EFT Manual (Everyday EFT: Emotional Freedom Techniques) by Gary Craig.

The British Holistic Medical Association website

Contact the specialist **Cardiac Liaison Nurse** at your hospital if you have any worries, concerns or questions before or after surgery.

Most hospitals have a **Patient Advice and Liaison Service** that can be contacted if you would like help to get information, express a concern or take forward a complaint.

Don't forget the Somerville Foundation's website and facebook page as well as the

Somerville Foundation Helpline:

0800 854 759.

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(July 2011, updated 2019).

www.sfhearts.org.uk