

# LET'S GET READY

A Psychological Guide for Childhood Cardiac Surgery





**Your child has a  
cardiac condition.  
At times it can feel  
overwhelming...**



**...this guide aims to calm the waters and help you navigate the path ahead.**

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# INTRODUCTION

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Catherine has been working with families attending the cardiac service at Children's Health Ireland at Crumlin for over 20 years. Let's Get Ready was written to support families through the challenges of cardiac surgery. This book applies psychological theory regarding stress management and resilience building for parents, as they support their children on their cardiac journey.



# PREPARATION FOR PAEDIATRIC CARDIAC SURGERY

**To all families from the North and South of Ireland, welcome to your psychological guide to cardiac surgery at Children's Health Ireland (CHI) Crumlin.**

This guide aims to support you as parents/caregivers in preparing **yourself, your child** and **your family** for heart surgery. As psychologists with the cardiac team at Children's Health Ireland at Crumlin, we are part of the multi-disciplinary team approach to preparing you and your child for cardiac surgery.

It is our privilege to be part of your cardiac journey. We want to support parents/caregivers to achieve your goal of securing your child's optimum cardiac health through surgery while maintaining you and your child's emotional health.



## A PSYCHOLOGICAL ORIENTATION TO PREPARATION FOR PAEDIATRIC CARDIAC SURGERY

This guide will help you to recognise your unique emotionally protective role as a parent/caregiver. You will realise that you and your child are part of your cardiac multidisciplinary team including **surgeon, cardiologist, nurse, ICU doctors and nurses, clinical nurse specialist, psychologist, social worker, physiotherapist, occupational therapist, play specialist and music therapist**. Your unique team aims to optimally support your child's cardiac and emotional health.

It can be daunting knowing where to begin and what to say or do to prepare for the surgical challenge ahead. Most parents want to prepare their child for surgery but don't know how. Often parents/caregivers are worried that they will upset their child before surgery. **There is much to consider. Take your time working through the guide slowly so that you can digest it and make it your own.**

This guide aims to give you the **confidence to prepare** your child of any age for cardiac surgery. It is hoped that by recognising and enacting your emotionally protective parenting gift, your child is more likely to meet the surgical challenge with less stress and without trauma.

This guide aims to help you identify how to prepare your child including suggestions of **what to say** and **what to do** to actively cope with all challenges in hospital.

It is hoped once you identify and own your valued role, that you will **feel and act more confidently** with your child and with your cardiac team.

**You know your child best.** You are best positioned to work as a member of your child's surgical, medical and nursing team to ensure the **best result medically and psychologically** for your child.



# TAKING CARE OF YOURSELF



# PREPARE YOURSELF AS PARENT/CAREGIVER FOR YOUR OWN SURGICAL JOURNEY

**Let's pause and think about self-care** and preparation for you as a parent/caregiver. There is a saying 'you can't pour from an empty cup' and so it is important to take stock of your own resources and coping strategies first before you can begin to think about supporting your child's coping.

Typically, it can be difficult to disentangle yourself from the busyness of your everyday life pre-op at home to take on the emotional and practical tasks of readying yourself for surgery. It is however vitally important that you do. **Parents can find it hard to make time for their own emotional needs** but when they do they will actually benefit themselves and benefit their child too. So, if you find it hard to prioritise your own emotional needs with yourself in mind allow yourself do so for your child's benefit!

## Ask yourself 'how do I feel now about my child's upcoming surgery?'

It is typical to **feel numb** and the prospect of surgery to feel unreal. You may be waiting for the doctor to say it's all been a mistake your child doesn't need surgery after all! You will need to move from this state of disbelief and emotional disengagement through to **feeling loss** of your child's healthy heart and need for surgery.

Most parents harbour a silent **sense of guilt**, as if they were to blame for their child's need for surgery. It is interesting that most parents would reassure another parent that they were not to blame for their child's health condition, but they find it hard to show compassion for themselves! This contradiction should be challenged as it is factually incorrect and emotionally depleting.



**Anxiety, anger and fear** typically need to be expressed safely. Shedding tears can help you to let go of avoidance and move to some **acceptance which fuels active coping**. In many ways you need to be your own brave emotional coach. You can collaborate with others to gain support and advice including Children’s Health Ireland, at Crumlin Cardiac team, The Royal Belfast Hospital for Sick Children Cardiac Team, Children’s Heart Beat Trust, Heart Children Ireland and other support groups. A **counselling** relationship might be valuable at different stages of your child’s heart journey.

Let’s think about our **hierarchy of needs** as human beings. We all need to have somewhere to rest, eat and take care of our basic needs before we can be available to other needs such as coping with intellectual tasks i.e. medical updates and how we feel about these. Considering your many normal needs this can help you to plan your own preparation for a hospital stay. E.G. ‘Where will I rest?’, ‘what will I do to calm myself?’, ‘who will I talk to about my fears and upset?’

## Prepare for your inpatient stay as well as your child’s

Open a suitcase and start to fill it over time. Pack comfortable clothes and shoes for yourself on the ward. **Pack all your creature comforts** from indulgent snacks, healthy nourishing snacks, a refillable water bottle, shampoo, moisturiser, nail file and lip balm for you and your child, your favourite bedding for the best night sleep possible. Pack your own earphones and iPad to enjoy some well-earned time out by listening/watching something relaxing or distracting. **Rest** even without sleep can be **rejuvenating** and help you to choose what to focus your efforts on during this complex and busy hospital stay.

## Preserve your emotional energy

Consider planning to write one text per day giving family an update. You could send the same text to everyone or you could **send one text** to someone you trust so that they may circulate it for you. You could include that you will not have time to respond to individual texts. This will help you preserve your energy for yourself and your child.

## Parent to parent support

It can be helpful talking with other parents who have completed a similar surgical challenge. You may relate easily to their advice and support as **'they have walked in your shoes'** so to speak. When talking with other parents who are in hospital at the same time as you, be aware of the emotional risk when you may take on another family's stressful medical journey as well as your own. Some parents choose not to make intimate connections in hospital until their child is well on the road to recovery and their own worries are far less.

## Let your past inform your future

It can be profitable to think about your previous life challenges either medical or non medical and to reflect on your **coping strategies** individually and as a parenting couple. Consider what coping strategies worked well for you and also what you would like to change during your next surgical challenge.

Consider actively working on **self-calming and rest** giving coping strategies such as mindfulness, meditation, exercise, relaxation and deep breathing. These skills

need to be well practiced so they come easily to you in hospital when stressed. You will fuel your best thinking and perspective taking when you are calmer.

## You as part of a parenting couple

Consider yourselves as a parenting couple. Consider the different and the similar **coping strategies** you share between you. These may be **similar and compatible**, or **dissimilar and complementary**. At times these coping strategies can be incompatible and can irritate or add to stress levels. It is wise to discuss this and to identify your coping strengths and vulnerabilities while recognising and **respecting the strategies of your parenting partner**. Coping strategies can include how much information you want to know and discuss. Some parents like engaging in medical details to feel more in control. Not to discuss this would cause them to feel out of control. However, their parenting partner may feel overwhelmed by medical details and want information on a need to know basis. Even though one parent/caregiver may not like discussing risks and worries, they may be grateful that someone is looking out for these issues.

## Your parenting gift

Consider your special parenting gift to your child, e.g. ‘**my child relies on me for comfort and calming**’ or ‘**my gift is one of fun and distraction**’. Own your valued parenting contribution and discuss as a couple when and how your child can best benefit from these. If you are particularly anxious about needles etc you may choose to work on this before surgery so that you may be available as a calming influence during your child’s procedure. If it is not possible for you to remain calm you can divide up the parenting tasks with your parenting partner.

## Take stock of other life demands

What other life challenges exist for you and work to minimise these ahead of surgery. Look into leave from work. Look into **financial supports** that may be available. The Cardiac Medical Social Work Team is available to discuss these issues with you.

## Ask for help and accept help

Draw on your family and friends as your support team. **Lone parent/carer** consider inviting a relative/friend to join you in sharing this hospitalisation. Ensure you have

emotional and practical supports for the surgical stay **e.g. someone to call** or meet for a meaningful chat and someone to provide home **cooked meals/laundry and someone to mind siblings**.

## Prepare for the unexpected

Prepare for a longer stay than expected to minimise disappointment if there is a delay in discharge. Expect a set back in your child’s post op recovery as normal. When it happens you may be better able to recognise it and not panic. **‘This is our set back we’ve expected it, this is all part of the process, we are not going to panic, we will take it day by day.’**

## Visualise your goal

Move forward in time in your mind’s eye to achieving your goals of the surgery going well and leaving hospital. Pack a **celebratory going home outfit** for you and your child to wear. Imagine the smiles and the tears of joy as you leave the ward and travel the familiar roads homeward bound. Imagine **your child’s heart healthier and stronger**. This can help motivate you to move forward more positively towards the goal of surgery.

# PLACES NEAR YOU, FOR YOU



CAFE

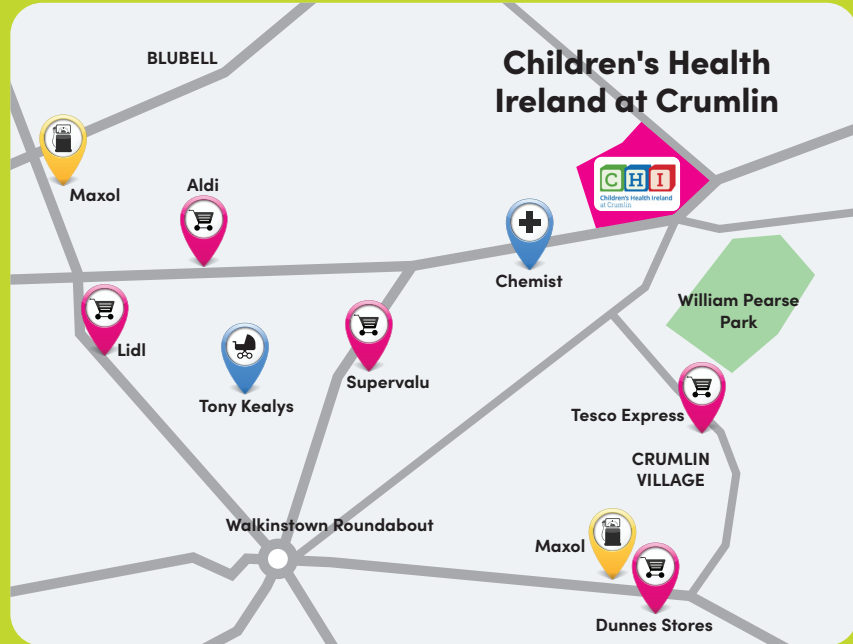


FRESH DRINK

The **hospital canteen** is open to parents/siblings for breakfast 8.30am–11.00am and lunch 12.00pm–2.00pm Monday to Friday.

**Market Kitchen café** beside the hospital canteen is open 7.00am–6.00pm Mon–Fri and 7.30–5.00 Sat–Sun

The **Woodland café** near the A&E is open from 8.00am–4.00pm Mon–Fri



INTRODUCTION

TAKING CARE OF YOURSELF

PREPARING YOUR CHILD

WHAT TO EXPECT



# PREPARING YOUR CHILD

## WHY PREPARE FOR CARDIAC SURGERY?

### Ensure a positive psychological outcome

Through a challenge such as cardiac surgery there is the opportunity for a positive psychological outcome, but there is also risk of a negative psychological outcome.

It is hoped that you too will see that there is indeed

**opportunity in challenge.**

Throughout this guide to preparing for cardiac surgery we hope to support parent/caregiver in recognising that active anxiety and stress management is **your protective parenting gift.**

When you have developed a personal, informed, explicit and collaborative plan then you and your child will cope better with hospital treatments. When you and your child actively prepare for surgery the surgical journey becomes **more known than unknown** and you will both feel more **in control**. When you feel more in control you will be more able to take action to **dial down the stress** levels experienced with treatments in hospital. It is more

likely that a **positive psychological outcome** is possible for you and your child.

### Building resilience

Resilience is the way of coping with stress and adversity that is protective against becoming overwhelmed and experiencing trauma. Ahead of surgery you may try to put into your own words **what you would like this surgical experience** to represent for you and your family. This can be your anchor, one that can guide your actions before, during and after hospitalisation.

E.g. **'This surgery represents how we pull together as a family and face into an extraordinary challenge to secure our child's health with courage and commitment'.**

## Opportunity in challenge

Imagine if your child could put words on their experience. Broadly speaking, there are two possible psychological outcomes post-surgery. Once you have read them, you will agree with all other parent/caregiver that there is only one outcome that you want to strive towards for your child.

We worked honestly together as a family. I felt safe even when treatments were painful because I was prepared for them and I could trust my parent/caregiver to be honest. I felt heard and responded to. I am proud of my surgery story. I think of my surgical scar as a sign of my strength and courage. I feel like my surgical scar is a positive part of who I am. I may be more likely to take on future proposed treatments, interventions and self-care tasks because I value them and I now know I can handle them.

VS

I feel traumatised. The whole experience was too much for my family and me. I felt subjected to treatments. I lost trust in my parent/caregiver because they didn't prepare. I never relaxed as I never knew what was coming next. I ended up feeling helpless and depressed. I now hate my scar and I can't even look at it. I never want to go back to the hospital again. I fear another surgery will be sprung on me! Even an outpatient appointment feels threatening to me now! I feel so overwhelmed that I don't think I could take on future cardiac treatments, self-care tasks and medicines.



## A Word (or 3) about stress management

It is helpful to know about the **Three Systems** that can naturally be activated within us anytime when dealing with any stress or challenge in life. These psycho-physiological systems have **developed in everyone to keep us safe**. It is helpful to know that what we experience, think, believe and know can actually have a physical impact on us. We can learn to actively manage stress. Once we better understand these normal emotional reactions we will then be in the best position to know what we and our child need at any time.

1

There will be experiences that will activate the **THREAT SYSTEM** e.g. when you and/or your child will feel threatened or anxious about a nursing/medical/surgical treatment.

When we feel threatened or frightened in anyway this usually releases the hormone called adrenalin into the body so we can protect ourselves. It is known as the **Fight, Flight or Freeze response**. Your child may try to avoid the treatment and fight their way verbally or physically away from the threat. This is a natural

reaction and you will aim to **minimise activating this Threat System** in the first instance by honestly preparing for surgery at home and discussing the reason for each treatment, describing how it will feel and for how long. You and your cardiac caring team will also aim to soothe and to help your child recover after their threat system has been activated.

When the threat system is activated the heart rate increases and the blood flow is diverted more to the limbs to help with an escape. **There is diminished ability to learn and to understand language**. This is important to know because even your most helpful suggestions may fall on deaf ears! Adrenalin levels usually drop when we move and burn it off or when we actively calm or soothe ourselves. Calming and soothing actions and thoughts can start the production of hormones that support calm and considered actions. Once we understand this normal physiological response to stress we realise that we need to practice hospital coping strategies at home. In a relaxed atmosphere your child's full cognitive capacities are alert and they can better understand the task at hand.

Acceptance, resolved,  
believe in possibility,  
manageable, safe,  
mastery, control

2

**Drive**      **Achieve**  
**Goals**

Calm, safe, secure,  
protected, manageable,  
heard, witnessed

3

**Safe**      **Calm**  
**Soothing**

1

**Fight**      **Freeze**  
**Flight**

Fear, worry,  
overwhelmed, in danger,  
pain, injury

2

The **DRIVE SYSTEM** is activated by anything that motivates you and your child. This includes anything that is desirable and gives a sense of excitement and personal achievement. For example, when you and your child engage in realistic joint goals e.g. having a surgery **'to help me run faster'** or **'to ride my bike'** or getting a cannula inserted **'quickly with a little ouch'**. Once motivated you will organise your intentions and behaviours around these goals with focus and ownership. A hormone called dopamine is released into the body. Dopamine is a feel-good hormone that can help balance out other hormones of the threat system. Interestingly **after shedding tears dopamine is released**. It is as though after acknowledging and expressing our loss or sadness then our body fuels our coping. So don't fight back your tears or stifle your child's tears.

3

The **SOOTHING SYSTEM** is prompted by any nurturing behaviour including being supported with empathy and compassion by others or by yourself. Oxytocin and endorphins are feel good or love hormones and they are released into the body to promote self-calming. Soothing can be achieved through supporting your child through practicing self-calming or **relaxation techniques, reading, singing, using guided relaxation or deep breathing**. Physical soothing such as hugging, rocking, massaging are all helpful. Also finding a way to move on from a stressful situation to a soothing situation by using distraction, rest/sleep or play. Compassionate acts and compassionate statements can help to self-soothe.

In hospital you can try your best to carve out nap times and quiet times on the ward so that your child's threat system can be calmed and the soothing system activated. Collaborate with your nurse each morning to know what treatments are needed that day, and when a quiet time can be carved out.

## Goals of preparation

The goals of preparing your child for their surgical stay are to help your child **feel more secure, reduce worry and support active participation** during their pre-operative (**pre-op**) time and **post-operative (post-op)** time in the **Cardiac Day Unit (CDU)**, the **Intensive Care Unit (ICU)** and the **Children's Heart Centre (CHC)** and back at home again. Preparation for cardiac surgery is associated with less PTSD, post traumatic stress disorder as challenges are known, anticipated and coping strategies are well developed.

**Preparation is associated with optimal emotional coping during and after a hospital challenge.**

## Where to start?

### Children's worries

Let's think about the child's experience of surgery and why we need to help them negotiate this emotional and physical journey. Start preparation by making time to talk about surgery and hear your child's concerns. This will provide you both with a shared starting point from which to work from. You will need to ensure that you **give enough time and space to hear your child's concerns** so that you can come up with a coping plan together. Oftentimes parent/caregiver can tell that their child is worried about something. Children and even teenagers often do not have the words to express their fears. Once these concerns are better understood you both can be motivated to work towards doing something to reduce fear and to promote a sense of control and mastery over the situation.

## Parent/caregiver lead by example

Take responsibility and initiate the discussion regarding an upcoming surgery. It is too much pressure to expect a child to **break the silence** on this subject. Their silence does not typically mean they have no thoughts or concerns on the matter. Volunteer reassuring information about the team, about decision making and how parents/caregivers will help negotiate treatments with staff. This can provide a better sense of emotional and physical safety. When parents/caregivers initiate these discussions it gives children the permission to express their concerns. This can be the start of **an honest, emotionally safe and collaborative relationship** through the cardiac surgery experience.

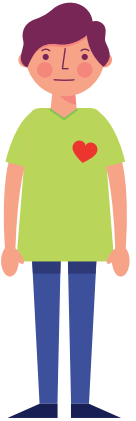


The **younger child's** worries typically relate to **pain, needles, unknown staff and separation**. Your realistic preparation will have to include acknowledgment of these aspects of the hospital experience and make plans to cope with them. Strategies for dealing with all these challenges are discussed later.

**Older children** naturally worry about the pain of needles, chest drains etc but they have the cognitive capacity to think further. It is typical for the older child to worry about the anaesthetic or sleepy medicine. They worry that they **will wake up in the surgery** and feel pain and be frightened. It is worth addressing this maturely explaining in **developmentally appropriate language** about the **sleepy doctor/anaesthetist** whose only job throughout the surgery is to keep your child comfortable and asleep. They take the child's weight and height so that they can scientifically calculate how much sleepy medicine is needed and it is given continuously throughout the surgery.



The **teenager** almost always worries about waking up in surgery and goes on to **worry about not waking up** ever again i.e. dying in surgery. It is important to allow the older child express these concerns. Imagine the **emotional isolation** experienced if a teenager was left to consider these concerns alone. It can be reassuring to discuss how the cardiologists and surgeons have done many pre-op tests including blood tests, ECG, ECHO, CT scan, x-ray, MRI, 3d scan, cardiac catheterisation and



they are prepared for the surgical task. They have shared their cardiac information from the Royal Children's Hospital Belfast cardiac team and Children's Health Ireland at Crumlin cardiac team. They have discussed and agreed what kind of surgery is needed and when is safest. **No one person has decided this but instead a team have come to a clinical agreement.** Allow the teenager to put questions forward to the surgical team so that they may trust what their parent is telling them. Then it is a matter of allowing the strong emotions of fear and worry to be expressed and supported. Tears will need to be shed. Some teenagers go as far as arranging a bucket list of activities before surgery and sharing with family and friends how much they love them and value them in their lives as they want to safeguard against having any regrets.

You will need to discuss **teenager's** typical concerns about **pain management, privacy, physical modesty and how to toilet** post op. Whenever possible teenagers are given individual rooms for privacy. The team try to preserve their modesty. Pain relief is given into the IV drip in ICU and then given orally on the CHC. Discuss how

a urinary catheter will be put in when they are asleep for surgery and how it is not painful to take out. A bed pan or commode is also used for toileting. Just think how much more relaxed and in control your older child will feel when they know that you, their parent/caregiver is realistically preparing step by step for the challenges of hospital. When they see and hear you actively prepare, it provides a sense of relief and reassurance that they are not alone in being alert to these issues.



**WHAT TO EXPECT**

## CARDIAC DAY UNIT (CDU)

### What treatments to prepare for and when

#### When on the Cardiac Day Unit (CDU)

The day before surgery expect to be offered a pre-op day to come to the CDU and update all your child's tests. This typically involves a blood test, a cannula, nasal swabs, swabs of the under arms and groin, ECG, ECHO, temperature, blood pressure and listening with the stethoscope, talking with the anaesthetic team and the surgical team.

You will notice that what you and your child experience on the first day in hospital on the CDU will be repeated again and again throughout your stay. When you have prepared coping routines, to help treatments go 'quickly with a little ouch/pain' then you will have **launched your coping campaign successfully by getting it right first time and every time!**

You will also have the opportunity to meet the **Play Specialist** who will show you special books and dolls with the relevant medical equipment. This will help to make sense of the upcoming experience. You will have an opportunity to meet with any other team members CNS, psychologist, social worker etc. The day is very busy and tiring. You will usually be admitted to the Children's Heart Centre overnight and your surgery will take place the next day.

On the day of surgery a '**pre-med**' i.e. an oral medication to relax your child before going to surgery is available. This is a small amount of liquid medication that does not taste great. If a cannula is not already in place one will be inserted before surgery. Your child will need to





only wear a surgical gown. When in the anaesthetic room you can prepare for sleepy medicine into the cannula. Sometimes a mask with sleepy gas can be offered, but this is less typical.

### When in the Intensive Care Unit post-op (ICU)

Prepare for a central line in the neck (a cannula with 3 tubes coming out of the top), a cannula in each arm, 2 chest drains, 1 pericardial drain, pacing wires, urinary catheter, nasal gastric tube (N.G.), ventilator then nasal oxygen prongs, ECG stickers with wires and the special plaster over the surgical wound. Your child will be encouraged to sit up in bed or in a chair to help their breathing and recovery. Most of the medicines are put in the N.G. tube or cannulas but some will need to be taken orally. Innohep, a blood thinner, is injected daily into the thigh until the chest drains are removed. **The time in ICU can be partially or completely a remembered experience** and so all medical aides need to be understood to be emotionally managed. Rarely a child can be awake and ventilated and so their voice cannot be heard. Bring a notebook and pen for your child to write on and prepare some gestures to communicate.

### Back on the Children's Heart Centre (CHC)

Parents/caregivers can stay with their child 24/7 and a couch-bed is provided on the CHC. The first few days back on the cardiac ward can be **intense** with what **can feel like continuous treatments**, tests, ECG (Electrocardiogram), ECHO (Echocardiography/heart ultrasound), N.G. X-ray, blood pressure, temperature, medications and **physiotherapy** requests to sit in a chair, stand up and walk around the ward. Doctors and nurses will ward round into your room every day. The Central line and N.G. will be taken out soon so medicines will then have to be taken orally. Once the central line is taken out any blood tests will have to be done from a vein. A new cannula will need to be inserted too. It is a safety standard of care in case of an emergency that a working cannula is always in place even when it is not being used as part of the daily routine. Innohep injections will continue until chest drains are removed and when warfarin is at its therapeutic level (only if warfarin is necessary). If your child needs warfarin regular blood tests are needed to achieve the therapeutic level and dose.

## Imagine yourself a director of a movie scene. Plan to ensure helpful steps are taken to ensure a positive ending to your scene!

Each treatment can be supported by you and the caring staff member i.e. nurse or doctor. A Play Specialist can support you in preparing and during the treatment. Choose from the following coping strategies:

1. Distraction; by watching TV, playing a video game, counting, singing, listening to music.
2. Touch; use massage, holding or patting.
3. Music; sing or listen to music.
4. Relaxing Breath work; blow bubbles and practice deep breathing to calm and soothe.
5. Relaxation; follow a practiced guided relaxation, progressive muscle relaxation training.
6. Ensure you, as parent, are the one who is physically the closest to your child, i.e. snuggle in beside them in their bed.
7. Ensure your child is sitting up for treatments (where possible), as they will feel less vulnerable.
8. Meet your caring team at the bedroom door and clearly understand what treatment is needed. Then turn to your child and translate into phrases they

understand. Explain what does this treatment look like, taste like, feel like, how long does it take, where does it go?

9. Repeat treatment description, point and use gestures to aide understanding. Where possible, have only one person talking at a time, one person in the room and carrying out the treatment.
10. Politely ask your caring team to wait until you and your child are set up in the practiced and comfortable position and with the supports needed.
11. Give choices regarding e.g. taking off plasters, which arm for the blood pressure monitor, use of topical anesthetic spray for blood test or the order of treatments where possible.
12. Holding; use practiced and agreed holding with your child for safety and quickness, avoid restraint.
13. Give rewards for effort as well as success.
14. Allow shouting or crying when it helps to stay still.
16. Use the 'Ready, Steady, Go, Stop' technique, where possible.
17. Use the 'When....Then....!' strategy. Negotiate what treatment needs to happen first and then what reward/activity/rest comes second.



## Medical play

Your child can play at being the nurse or doctor. Watch how your child acts out this role. Do they show caring and gentleness or do they use the medical equipment in a rough way? **This may help you to better understand their belief about the treatments or the people involved.**

Ask them what they think the nurse is doing and their intentions. Explain what they will actually be doing and what the nurse's intentions really are.

**In the pharmacy you can buy medical equipment that will help your child acclimatise to hospital care;** orange hospital grade taping to play at securing a cannula, cold/numbing spray that gives a slight numbing effect to the skin where a needle is intended, remove wipes to practice dissolving the stickiness of tape and bandages. These daily tasks in hospital are typically a great source of anxiety. At your next hospital, appointment ask to keep your used ECG stickers, used oxygen sats (sats=saturation) probe and ask for some cannula tubing. Make your own 'cold spray' using a spray bottle with ice water too!

## Play it out

The next step in preparation is to play out a routine with your child for each nursing care. You will also be able to work on a plan of how to make the task **'easier, more gentle/a little ouch and quicker'**.

Get the **whole family involved** in helping your child to get used to these nursing tasks and to the equipment on their body. Helpful siblings and carers can walk around with cannula tubing taped to their arms, plaster on their mid chest (representing the surgical scar area), and a plaster on their neck (indicating where the central line will be). Families often use regular straws taped to the chest to indicate chest drains. An I.V. drip can be made out of a plastic bag used for clothes and a straw! Pull the curtains and have a parent lie on the couch for an ECHO. Hand gel or hair gel can turn into 'jelly on the belly' for an ECHO along with an old T.V. remote control as the ECHO wand! Dolls and teddies can be patients too.

By **working together** the reluctant child will passively watch and hear others play out the scene. They get to know about the equipment, their function and the helpful routine **'to get the job done super quick'** and **'gently'**. Regular passive exposure can begin to prepare and reduce stress. If your child says **'No'** to medical play, don't force them but instead continue to play and discuss the equipment together as a family. You need to confidently lead the way for your child. Your child is more likely to accept the medical play as it is valued by you as a family.



## The Big Three

### 1. The blood test, 2. The cannula, 3. The Innohep injection.

There are three cares that will likely dominate the younger child's mind while in hospital. You can help dial down the anxiety by preparing routines at home together.

1. Offer a sound rationale for these treatments.
2. Plan how you hope to proceed. Like an actor **play out explicit step by step approach at home** to achieving these treatments.
3. When in hospital **be very honest** about when there is a need for these treatments to maintain trust and support.
4. Your child will need a blood test and cannula from the first day on the CDU so practice at home and put your practiced routine into action with collaboration with your team. This way you will **get it right the first time and every time!**

## The blood test

Pretend you are all actors and prepare a routine at home. Sit your child sideways on your knee. Your arm around their back and holding their outer arm. For an older child snuggle in close holding their arm still with their agreement. Aim for a “fast blood test with a little ouch”. Practice using the cold spray at home so its usefulness is understood and so the coldness is not startling. Each blood test container takes 5mls of blood or less. Show how much this is i.e. a tea spoon with Ribena. Explain ‘your body is clever and will make new fresh blood’. Practice your chosen distraction techniques e.g. playing an interactive game or massaging etc.



## The cannula or ‘Freddie’

The cannula is playfully known as ‘a freddie’ in Crumlin. Most children think that the needle used to pierce the skin stays under the skin. This is not the case and it should be clearly shown that the needle and tiny straw go into the vein and the needle immediately comes out leaving the soft bendy straw in the arm to **‘have a drink’** i.e. so medicine can be put into it. Cannula tubing, without needles, can be played with and water can be syringed through it in a playful manner to illustrate its function. The helpfulness of the cannula should be pointed out; **‘the cannula gives you your medicine without having to put the medicine in your mouth!’**



## Innohep/Heparin Injections and oral Warfarin

While your child has chest drains they will typically get an injection of a blood thinner called Innohep into their thigh each day. This is not comfortable but the pain should be fleeting. Use the same comforting hold as you use for a blood test but this time hold their leg. It is often the anticipation of pain that can be worse than the reality, as is the case with most nursing cares. You can try to explain the function of this injection. If your child is on oral Warfarin the rationale can be the same.

**‘The Innohep injection/warfarin helps make your blood run fast around your body which is good’.**

**‘You can choose which leg you want the injection in today. Do you want to try some cold spray to make it a smaller ouch? Let me snuggle in beside you to help you keep your leg still so you can get this job done quickly. I’ll tell the nurse to wait until we are ready. I’ll say ready steady go, it will be done, what treat or activity will you do next?’**

Once your child does not need their chest drains they can be removed under sedation on the ward and you no

longer need daily injections. Depending on your child’s heart condition and surgery they may need to take oral Warfarin which necessitates regular blood tests initially to ensure that there is the correct amount of Warfarin in your child’s blood stream.

## Chest Drains; ‘Bubble Box’

Chest drains are typically one of the biggest challenges for children. Children typically find them overwhelming to look at. They fear anybody touching them least they cause discomfort. Chest drains typically cause a temporary pain when your child tightens their muscles around the tube in their chest to sit up or stand up. This pain should be transient. Very rarely do chest drains cause continuous discomfort. Some children even show little to no discomfort, although this is more rare. Plan for the **Cardiac Physiotherapists** to come to ICU and help your child out of bed and to walk with chest drains and bubble box.

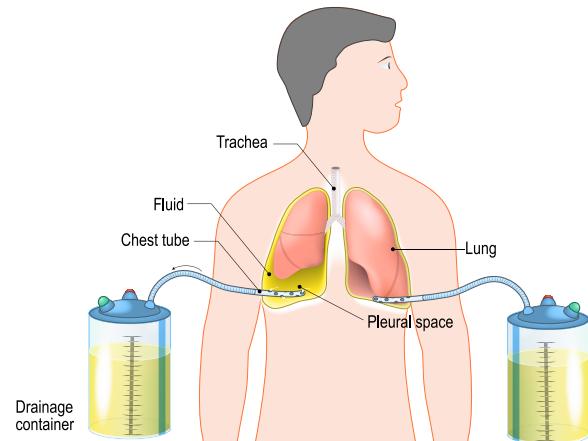
You can prepare for chest drains by making home-made chest drains e.g. using drinking straws or any tubing materials. Practice preparing for some pain on

movement from lying to sitting or standing **'ouch 1,2,3 sit up, ouch all gone'**, **'Ouch 1,2,3 stand up, ouch all gone!'** When post op in hospital discuss how **'it looks sore'** but **'it is not always sore'**. Acknowledge that **'you are worried that when you walk with chest drains it will be sore'**. This is important to help a child and parent distinguish between anticipatory anxiety of pain versus the actual length of time in pain or discomfort. It really helps to respond and support in a calm **'can do'** spirit which can help to positively fuel your child's coping.

The function of these drains could be explained in a developmentally sensitive and honest way e.g.

**'After an operation some of the old blood and liquid needs to leave the body. If it stays in the chest it will make you cough. Just like when you fall and hurt your knee, we wipe away the blood and we don't try to put it back in your body! Try not to worry too much because you have a smart body that is making lovely new fresh blood.'**

When your child is sitting out in a chair, ensure your child is not gazing at their 'bubble box' (friendly name for drainage container) with all the fluid collecting there. Ask for the bubble box to be moved to the side out of sight. Also have cotton pajama tops or soft shirts with buttons down the front to easily put on when your child first sits up in ICU. Covering up your child's chest can be a welcome relief from the physical and visual aspect of after surgery. Teenage girls may appreciate wearing a loose cropped tee-shirt under their pyjamas instead of a bra to provide extra modesty. A button shirt can allow your caring cardiac team easy access to the chest area.



## At every treatment ask...

### **‘What can I do (parent), what can you do (child) and what can the nurse/doctor do to help now?’**

Explain the reason for each treatment to your child and help them make sense of their experiences. Prepare for how to manage specific nursing/medical cares. Prepare by acknowledging how they will feel about each care. Name the emotions of **‘scared, sad, angry’** or **‘brave and strong’** before and during hospitalisation. This will help to normalise these feelings. It will also prepare you and your child for how they would like to be supported at that time. Make an explicit plan together that brings a feeling of soothing and safety.

E.g., **‘what will I do to help when you are feeling scared? How will I know when you are scared?’**

**‘I could ask the nurse for a little break’, ‘I can snuggle in close to you’, ‘you could play a game on your phone during a treatment’.**

**‘You could shout if you like and you can cry if you like’.**

## Distraction strategies

Deep breathing, counting, singing, giving a hand massage, watching a favourite programme etc are all good strategies to help negotiate your child’s way through a treatment. You will need to agree and practice these strategies at home before surgery so that the challenge is well understood and you both can invest in your choices as to how you and your child will weather this treatment.

You will then have the opportunity to pave the way for your child to access the potentially positive self-soothing interpretations and emotions which are also available throughout the surgical journey.

E.g. **‘How will you feel when the injection is finished? ‘Will you feel proud of yourself, will you feel happy or will you feel glad its over?’ and ‘how would you like to celebrate doing this hard work?’ ‘will you cry with tears of relief that it is all over?’**

You will achieve this realistic sense of preparedness in the calm security of your home environment before they enter the foray of the hospital with its continuous pace of nursing and medical care.



## How to protect your child's emotional journey

By preparing for surgery you will be more able to recognise the stress responses typically involved in pre-surgery and post-surgery experience. You will begin to recognise the natural thoughts, emotional and behavioural responses in you and your child. You will be more likely to see the opportunities to best manage these challenges.

## Parent as emotional coach

When you own your role as **your child's emotional coach** you will be able to walk your child through each predicted scenario. This realistic planning for how you and your child will best manage in the moment will provide a sense of **emotional safety and reduce the risk of trauma**.

Cardiac surgery is likely to be the most unique event in your lives. It is normal for you to experience an **emotional roller coaster**. Your child will too! Your unique role as a parent/caregiver is your ability to provide a sense of emotional safety for your child in hospital. You will help them weather even strong negative emotions. Your child

trusts you and looks to you for reassurance about what is happening and for help to better understand that it is both **necessary and manageable**. Feeling worried and scared is inevitable and so try to avoid denying these legitimate emotions as this can layer your child's emotional upset with yet another strong negative emotion i.e. guilt.

As a parent/caregiver you will need to move from a position of wanting and expecting to protect your child from having any negative emotions such as **worry, fear and sadness**. **You need to be able to help your child accept these negative emotions are normal in the surgical situation**. Encourage expression of normal negative feelings and your child will feel better understood. They will be more open to the soothing effect of your support and coping strategies. By actively parenting these negative emotions you can actually help to minimise their negative impact.

Talk about the events and **thoughts/beliefs** that led to their feelings. Talk about options of how to balance out or even contradict negative thoughts and beliefs. You will

realistically teach your child that **there is no such thing as good or bad thoughts and feelings**. You are equally available to support positive and negative thoughts and feelings. You will help your child let go of negative thoughts and feelings.

**Emotionally protective parenting is within your gift.**

Start practicing with everyday negative and positive issues. Think your thoughts out loud so that your child can see that feelings do not fall out of the sky but come from how we experience an event and what meaning we give it e.g. ‘when the door slammed I thought you did it on purpose and I was angry, but when you told me the wind blew it shut I no longer was upset!’ Your family’s emotional vocabulary will expand and the sense of understanding oneself and others better will develop. Your emotional connection will deepen as you become more attuned to each other through open collaboration. This will **deepen your child’s sense of trust in you** and in your relationship to soothe and manage upset.

**Name your feelings**

Use the chart below to help your child identify how they feel.



## Verbal and non-verbal expression of emotions

Your child will keenly analyse your verbal and nonverbal emotional communication. Trying to avoid certain topics, avoiding eye contact and being overly positive can often serve to place a child on alert. You have the option to join them on their emotional roller coaster honestly and openly by not denying upset, worry, fear and anger but by recognising these as normal. e.g. **'I'm really sorry but the chest drains can't come out today after all. I know this was so important to you. You must feel disappointed? You must wonder when will you ever get them out? I'm disappointed for you too. They will come out when you don't need them anymore.'**

Even after a tough day in hospital, make sure you take the time to sit with your child and review the day's challenges. Do make eye contact. Do allow quiet tears if necessary. Do let them know you are sorry if something didn't go well for them. Dig deep and name and claim the challenges and the achievements in a balanced way. Look for at least one positive response to a challenge. At the end of each day ask **'what was hard today and what**

**was easy for you?'** It is a good way of taking stock and letting go of negativity so that it does not overshadow the next day.

## Crying

Ahead of surgery, plan and pave the way for the **safe expression of tears**. Then plan together what you will do after tears have been released to help your child feel soothed and understood. Start practicing at home by calmly naming the negative emotions and allow safe expression. Encourage wondering about the thoughts and beliefs that led to these feelings and tears. Build a tolerance for slowing down these communications and **avoid rushing in too quickly with reassurance, distraction or negating emotions**.

Your child will need to cry during their hospital stay and it is perfectly fine for you to calmly cry with them to communicate empathy, compassion and understanding during this stressful time.

**Crying actually releases the helpful hormones endorphins** which helps fuel an answer to the burning

question; **‘what is important to me now?’** Tears can express strong and positive emotions of relief and joy of moving on.

Crying at the prospect of a treatment does not always indicate refusal or avoidance but simply upset and sadness. It is important to interpret the tears accurately, **‘You’re sad that it is time for a blood test, you don’t like those at all, but you want to get it done and so do I, let’s get it sorted!’**

This is the perfect time to plan a better day tomorrow by actively seeking to ensure a valued coping strategy is supported by the team

E.g. **‘let’s make sure we get a longer rest tomorrow’** or **‘let’s make sure we ask the nurse to show us what she is going to do before she does it’**.

### Emotional mismatch

An emotional mismatch can occur when parents/ caregivers are too jolly and positive, summarizing every treatment as **‘not too bad or it doesn’t matter it’s finished now’**. This can lead to a child building up

unacknowledged and unprocessed emotions which overwhelm. Typically, a child cannot manage any more challenge in this **emotion denying environment**. They can emotionally shut down, similar to a depression and reject all and any treatments. Or they can emotionally overreact forcing others to acknowledge their distress.

### Emotional saturation point for parents/caregivers

As a parent/caregiver, at some time during your hospital stay, you are likely to reach your limits in your caregiving relationship. Plan for this reality so that you can respond with compassion for yourself and all that you have managed to date. Notice you have reached your own emotional saturation point and you need a longer break from this stressful environment. Perhaps it is time to **swap with your caring partner** or ask **Play Specialists** to provide a session, **Children in Hospital Ireland Play Volunteers** are there to provide fun and a welcome relief from treatments. Your nurse may be able to help care for your child while you take a break from caring.



## Provide a motivation for surgery

Share an explanation for surgery. Use your family phrases so it really fits well for your child.

E.g. 'this operation is to help your heart grow stronger', 'we want the doctors to help you to run faster', 'we do lots to be healthy and we need the doctor to help us make your heart even healthier', **'your heart needs a service, a tune-up, an upgrade' or 'your heart will be stronger for longer'**.

Make a connection between surgery and what the child likes to do e.g. run, cycle, walk, climb stairs, pink lips and fingertips, travel more etc. Connect surgery with your family values as this can help it fit better.

**'In our family we always do what is good for us even if it's hard work'** e.g. **'we take our vitamins'** and **'we take our medicine'**, **'we eat broccoli'**, **'take exercise'**, **'go to school and do our homework'**, **'brush our teeth as the dentist tells us'** and **'listen to the doctor when they say a heart operation will be the healthiest thing we can do'**.

Talk about other family situations that were challenging and needed to be overcome, e.g. your child's previous heart surgeries or cardiac catheterisations, or another

members of the family's surgical/hospital experience.

## Forecast for challenge

If you have not forecast for challenge and discomfort as a normal part of the hospital stay your child may well catastrophise their experiences when trying to make sense of what is happening. This is not emotionally protective.

Your **younger child** may well conclude one of the following;

1. You, their parents/caregivers are bad and are allowing bad things to happen to them.
2. The caring staff are bad.
3. The child themselves is bad and you and the caring staff are punishing them.

The older child may feel unsupported and left to cope with their upset alone. Typically, they conclude that their parents/caregivers are emotionally unable or unwilling to acknowledge their emotional experience and that they are **left to cope alone**. They may doubt their parent's honesty. This is an emotionally vulnerable place.

It is common for emotionally unprepared children to physically **turn away from their parent/caregiver post-surgery in ICU and refuse to look at them or to talk to them**. This typically happens when a child is ill prepared for the surgical challenge and may signify their mistrust in their parent for allowing this reality to occur. This is a devastating experience, for both child and parent/caregiver alike, as they are emotionally lost to each other at their most vulnerable moment.

**Older children** often silently conclude that they must **protect their parent** from their negative feelings or worries as the parents/caregivers have not illustrated their ability to cope. They can also wonder why they were not told about the medical equipment on their body or the treatments typical post-surgery. They may well catastrophise any discomfort or pain as they were unprepared for it. Often, they silently conclude that **something has gone wrong medically** or the experience is known to be too much for them to manage. No one

wants to discuss the elephant in the room. They can **stay hyper alert, try to avoid sleep** and passively waiting for any verbal or nonverbal information to let them know that they will be alright.

These scenarios show that you can not take a child's silence and lack of questions as indicating they are happy with medical equipment and treatments. Gradually and gently parents/caregivers need to name each piece of equipment and name its function, stating it is '**normal after surgery, it looks unusual and it will be taken away when you don't need it**'.

Offer coping solutions, '**Will I cover up your chest with a sheet. Will I prop up the iPad so you can watch something instead of looking at the equipment all the time?**'

## ICU VISITING TIMETABLE

### ICU visiting hours for parents/caregivers only

7.30am–8.30am **No visiting for nursing shift handover report**

8.30am–1.00 pm **VISITING TIME**

1.00pm–3.00pm **Quiet Time no visiting**

3.00pm–7.30pm **VISITING TIME**

7.30pm–8.30pm **No visiting for nursing shift handover report**

8.30pm–10.00pm **VISITING TIME**

**Please be aware that these times are approximate as a medical ward round or nursing handover may take longer on some occasions.** Also, the cardiac ICU is a shared bed space, when another child is being transferred to ICU from theatre all parents/caregivers are asked to leave at this time for safety reasons. There are some procedures that are carried out on the ICU which will necessitate parents/caregivers to leave and this is once again for safety reasons. You can always phone ICU for an update on your child day or night.

### A special note about ICU

ICU is a challenging place for child and parent/caregiver alike. There are the obvious challenges of waking up from surgery to a body with many helpful medical equipment; cannulas, central line, urinary catheter, chest drains, pericardial drain, pacing wires and a surgical wound. There will be a new nurse every 12 hours to get to know. Therefore, all the previously discussed coping strategies are very relevant here.

## Separation

Separation anxiety is often the least talked about challenges of ICU. For children and parents it can sometimes out rank the fears and anxiety of treatments. ICU has a visiting timetable for parents/caregivers and so equipping your child with strategies to cope is important.

Here are some considerations when dealing with separation anxiety.

1. **Use imagery of a continuous connection between you** even separated to help your child feel comforted and safe. Talk about being in each other's hearts and minds even when separated normally e.g. for school, work, child care, sleep overs and bedtime etc. This will help to illustrate the temporary and safe nature of separation. Take a special soft toy, wash it in family laundry detergent, then **have a parent put their perfume/aftershave or scent on it**. Discuss how this toy represents the parent's continuous connection. Encourage the child to hug, smell and imagine the child and parent together doing something together.
2. When you need to leave your child in ICU, tell your

child explicitly that **you are not going home** without them. Leave something personal with your child to take care of during your absence as a symbol that you will indeed return. Tell them explicitly that you are just going to the bathroom or the tea-room and that you will be back. Tell them **you trust the nurse** and you want the nurse to mind them for a little while. Show your child how to use the call bell when they need their nurses attention when you are not there. Before surgery take photos of the parent's tea-room, bathroom door and your bedroom and show them these photos when you are leaving ICU. They will have an image in their minds as to where you will be.

3. You are your child's best emotional coach. By recognising how they are feeling you may not avoid upset completely but you will help your child feel their **worry is understood**. Openly talk about their feelings as being normal as this can pave the way for familiar calming strategies. Tears in anticipation of separation are normal and should be supported as such.



### Name their emotions and their worries

**'You are worried about me going to get my lunch and I understand that, but I am not worried because I want your nurse to mind you. Let's get you comfortable and put on a movie to watch. You are all set to manage without me for a little while until I am back. I will not leave the hospital. I am going up the stairs and into the tearoom. I'll eat my lunch and bring you something nice back with me. Will I bring your special pillow/ ear phones/something sweet?'**

Thank them for letting you go to get something to eat when you are hungry. Let them know they are doing you a favour and that you know this is hard for them to do as they are worried.

### Help pave the way for a positive relationship with your caring staff

Before coming to hospital, you and your child and indeed their siblings may work on a child friendly document **WHAT MATTERS TO ME**. Collaborate on information that will help your child's caring staff quickly get to know them and to form a more trusting and less stressful relationship. By working on this document your child will understand that you trust the staff and you expect to have a positive relationship with them.



## WHAT MATTERS TO ME!

Include some of the following;

- Your child's name and age.
- Names and photos of your child's family and of important people in their life.
- Include your child pet's names and photos.
- Include personal facts, school class, hobbies, favourite movie, TV program, music, game and friends.
- Include favourite holiday photos.
- Include important information about their favourite sleep routine, position in bed, cuddly toy, soother, blanket, lights, music, earphones etc.
- Describe what your child is looking forward to doing when they get home from hospital and are feeling stronger i.e. tapping in on their motivation for having a surgery in the first place, e.g. include a picture or a sentence about energy for e.g. bike riding, walking to school or having improved skin colour etc.
- If your child has particular phrases or words for items or people include these in your document as they will help avoid frustration in communication.
- If your child uses sign language or pictures to aide

communication include these.

- Include specific information about your child's sensitivities, special needs and concerns e.g.
- **'I am particularly concerned about my privacy and modesty'. 'I will be on the look-out for needles all the time!' 'I gag/vomit very easily!' 'I like to be told details of treatments. I like to watch injections/ blood tests'.**
- Describe how your child has prepared for treatments e.g. needles etc. so the team is consistent.



## What TO say about your caring staff

Focus on a team approach by asking **‘what can I do to help, what can you do to help and what can we ask the nurse/doctor do to help?’**

Ensure that you and the caring staff acknowledge the task as **‘hard work’, ‘sore’, ‘tastes bad’**. **‘You let me cuddle you tight and hold your leg still so the injection went quickly, that is the best way to get an injection, well done’**. **‘The nurse worked quickly so we could get this sore job done fast, thank you nurse for being quick’**.

This positive approach does not inadvertently malign caring staff or undermine their coping. Review the procedure when everyone has calmed down. E.g. **‘Could I, you or the nurse/doctor do something different the next time?’** E.g. **‘Would you like me, you or the nurse to say ready, steady, go so you know when to expect the needle?’** **‘Thank you doctor for helping us.’**

## What NOT to say about your caring staff

Avoid the following conclusions;

**‘That doctor/nurse is bold/naughty!’** **‘did they hurt you?’**. **‘The nurse is gone, now you’re OK’**. **‘Don’t worry anymore the nurse is gone now’**.

Parents/caregivers often try to reassure children by focusing on the care task being finished and the caring staff being gone. It may seem easier to associate pain or discomfort with an individual staff member and to keep yourself as parent in the clear! This can inadvertently fuel your child’s efforts to get the nurses and doctors out of their room. They may believe that it is their job to shout and kick to get the bold nurse away. This kind of support is unfortunately short lived as cardiac surgical care is intensive and so many caring staff will be treating your child around the clock. Furthermore, your child may well lose trust in you too because you keep letting the nurse/doctor return!

## What NOT to say to your child about a treatment

**'It's easy', 'it's not sore'** (when it is), **'don't cry,' 'it tastes yummy'**, (when it's not), **'It's nearly finished'**, (when it's not!).

These wishful statements e.g. 'it's easy" serve to undermine your trustworthiness as your knowledge is clearly faulty! It can also serve to cause self-doubt in your child's own interpretation of events.

Instead join your child's lived experiences with honest comments such as;

E.G. **'half of the bandage is off, well done', 'you've taken 2 out of 3 medicines, fantastic', 'you can take a rest from all your walking until this evening'. 'That was a hard one, you did it, well done', 'you feel like crying, that's OK, you are working so hard to get stronger after your big operation. You must be so proud of yourself. I am so proud of you. Let's ring granny later and tell her you took medicine that was yucky just like she does!'**

## How to prepare

So far we have done a whistle stop tour of the hospital treatments you will experience. To cope with these you and your child will need to gradually get to know these nursing/medical cares intimately at home first. This is part of the **acclimatisation and desensitisation** that helps to down grade the anxiety associated with a nurse or doctor working with your child. You don't want to leave any room for surprises.

You can start to plan for how you can successfully complete these **cares in a calm, paced and managed** way. These cares and the continuous 24/7 pace at which they are needed to keep your child safe and well are challenging to rest, sleep and play and so can be stressful. **Ask for your Play Specialist's involvement in challenging treatments.**

The option to say **'No'** to treatments post-surgery is not available but the option of **'how'** we get a job done is available. You are gradually steering your child towards active participation and towards a better sense of control.

Show, discuss and **play out** the different treatments. Discuss and illustrate what will it feel like, taste like and how long it will take etc. Break down the tasks into five minute conversations/play scenarios, using **medical preparation books**, medical equipment, medical play equipment and home-made equipment. Agree a name for each task/equipment so everyone is speaking the same language.

Name tasks and rate them **'Hard work'** or **'Easy work'**. Have an agreed strategy for each **'Hard work'** task. Act out the way you hope the treatment goes when getting a blood test or cannula sit your child on your knee sideways similar to a vaccination hold, your arm around them holding their arm/leg still with agreement. Sitting with your arm around them in their bed. Play out the agreed distraction technique. Play out a treatment using choice, 'ready steady, go. Stop' pacing techniques etc. You could also use a doll/teddy/sibling or other parent to illustrate an entire scenario before playing it out with your child.

## Urinary catheter

It is best to describe the urinary catheter's helpful function otherwise children and particularly teenagers are unnecessarily confused and upset.

**'The Catheter is like a tiny straw that goes in where your wee comes out. When you are asleep for your operation the doctor will put it in so you won't feel it go in. It helps measure your wee and this tells us about how well you are after your operation. Your nurse can take it out when you don't need it anymore. 'So go ahead and have a wee when in bed. It is not painful to take the catheter out'. It takes only about 10 seconds to come out. Everybody who has a heart operation has one!'**

## Nasal Gastric Tubes or N.G.

Prepare your child for a nasal gastric or N.G. tube to be in place when they come back from surgery. Tell them it's important that they not pull it out of their nose!

**'Every child who has a heart operation has an N.G. tube when they come back from surgery. It is there to help you after your operation when you might feel sleepy or sick and not want to eat or drink. It also helps you take medicine without having to taste it!'**

**'The N.G. tube goes in your nose down the back of your throat and into your tummy. When you can eat, drink and take your medicines all by yourself then you are ready to take out your N.G. tube.'**

**'Sometimes you can feel a tickle in your throat. Sometimes you can feel the cold medicine go down the tube. This is all normal and OK!'**

## X-Rays

After surgery it is typical to need a chest x-ray while in bed both in ICU and CHC. This can involve your child lying on a special hard board which is uncomfortable. **'The x-ray sees how your chest is doing on the inside. The hard part of an x ray is lying on the hard board for 30 seconds, otherwise it is just like getting your photo taken and you don't feel a thing!'** Advocate for your child by collaborating with your x-ray technician and make sure everything else is set up before your child is expected to lie down to minimise discomfort. This is another example of how you as parent/car giver can exercise your gift of stress reduction.



## Taking medicines

It is common for children who took medicines well at home before surgery to refuse medicines, even strawberry flavoured Calpol after surgery. When stressed it is harder to discriminate between a familiar and an unfamiliar taste. Oral medicine may represent something they can actually exert some control over by refusing to open their mouth's and swallow. It is important that you honestly prepare them for medicine that does not taste nice e.g. 'Calpol=Easy work, Antibiotic=hard work', 'the medicine you like , the medicine you don't like', 'bitter vs sweet medicine', or 'yucky vs yummy', i.e. **use your own phrase**. Typically only medicines your child needs to take after discharge need to be taken orally in hospital, all the rest go in the N.G. tube.

Try teaching your child to swallow tablets/pills before coming to hospital as this will avoid taking bitter tasting liquid medicines!  
**'You can drink some of your favourite drink before and after the antibiotic? You can take medicine little by little with lots of your favourite drink in between sips or all at once? Will I put it in your mouth or will you do it yourself? How about sucking on a chocolate lollipop or piece of chocolate and leave some chocolate on your tongue so only a little of the medicine is tasted? Let's practice the different ways now at home with all your treats so you will know what works best and we can tell your nurse!'**



## Children's Heart Centre (CHC)

### Cluster Care

Cluster care is when a nurse tries to cluster many interventions into **one visit** to your room e.g. I.V. (intravenous) medication, blood pressure, temperature, measuring chest drain output, oral medication, hearing how much walking, eating, drinking and toileting has occurred.

Advocate for Cluster Care with your caring nursing staff **when it is medically safe to do so**. Cluster care can ensure some quiet time during the day to **rest, de-stress** and recuperate.

**Consult your new nurse each morning** regarding the expected treatments and activities of the day so you can prepare yourself and together agree on how many cares your child can take in one visit.

**Share the upcoming daily cares with your child** so you can practice e.g. how to get a innohep injection in the leg, a blood test, medicines, new cannula, or where to take your walk. Your child will know if you are not sharing accurate information and will stay anxious and alert.





## Parent as carer

Negotiate with your nursing/medical team so you can carry out as many cares yourself including washing, oral medicines and supporting movements such as sitting up/standing up with chest drains/IV lines on your child's body. **Removing plasters/taping/ECG stickers** usually causes additional worry as there is risk of pulling the skin. A parent/caregiver can take as much time as is needed using **REMOVE wipes** so their child feels more in control.

Your involvement can help reduce the anxiety associated with these cares. Your child may well be worried about the proposed care causing pain, but added to this, is their **fear that the nurse/doctor will not recognise their pain** and continue with the treatment without pause.

You as parent/caregiver are more accurate at reading your child's facial expressions, tone of voice and so you can pace the speed of the care. You can discuss and negotiate rewards **'when ....then...'** with your child. You can carry out the **'ready, steady, go, stop'** strategy (see description below). This all helps your child feel safer.

## Parent as pace setter and translator

You as parent have a vital role in **slowing down interactions and treatments** with caring staff until you and your child become oriented to the challenge. Once your child knows what to expect they can carry out the well-practiced routines from home.

It is unfortunately possible for a child to **lose their ability to discriminate when stressed** and become overwhelmed. Remember when in fight flight mode your child will not be able to understand what is being said and will miss out on help. When this happens they can become more **continuously stressed and at risk of experiencing trauma**. Therefore honest preparation is important. Equally important are the agreed ways to emotionally support your child through these procedures. **e.g. take a break from treatment, decide the order of treatments when possible**. This should help your child to see the difference between a painful and painless task. This will have a positive impact on their ability to cope and recover.

Parents/caregivers may consider **meeting caring staff at the door of your room** on the CHC and CDU and hear about the treatment plan. In ICU when a care is needed, ask your nurse/doctor to **talk it through with first** so you can prepare your child. Reduce stress by increasing your child's understanding by using **gestures, pointing** to what you are talking about, **talk in short sentences** and **repeat key words**.



### **Example: Blood test**

**'We want a quick blood test with a little ouch. Just as we practiced I will cuddle in beside you to help you hold your arm still. When we are finished this job then you can get a treat from your treat bag. Let's play a game on the phone to distract you like we planned. Let me rub your other arm so you feel a smaller ouch.'**

**'Now nurse is looking with her eyes first. Now nurse is touching just with her fingers. Nurse is putting on the tight strap. They are cleaning your arm with a wipe. Nurse tell us 'go' when you have the needle. Will we count to see how quick we can be? Nurse, tell us when the blood test is over. Now let's get our treat for doing all that hard work. Let's have a hug /a high five/tears of relief, well done that was hard, you did it'.**

## Shorten the time exposed to a threat

When the blood test/cannula/innocent injection is finished and the nurse is just tidying away, if possible move your child's attention and eye gaze to you and the reward/or planned game/or meal. Start to talk about moving on e.g. **'let's go for a walk'**. This kind of agreed distraction is a great way to shorten exposure to stress and to move on. You will have helped to move from a threat response to a soothing response more quickly.

## Reduce the stress of Ward Rounds

Explain what is going to happen first. **'Here comes the doctors and nurses who want to talk about what to do next to help you get stronger to go home. Doctor are you going to just look with your eyes or are you going to listen with your stethoscope/check with your hands?'**

E.G. Point to your eyes and point to your chest gesturing with the stethoscope. **'The doctor is finished now'**, gesture a finished sign.



When any necessary physical exam is finished you can ask your doctor/nurse if you could **talk physically away** from your child. This can minimise your child's worry about a further examination.

If a child has not heard or has not been told in detail what to expect they typically will go into protective mode of **fight, flight or freeze and resist**. This can lead to strong, disproportionate and long response to relatively quick and non-painful treatments. By slowing down the interaction the child draws confidence from their parent/caregiver and from their own accurate interpretation and physical sensation. This will allow an appropriately mild reaction, e.g. to Calpol being offered and a stronger appropriate response, e.g. to a cannula insertion. The **trusting relationship** you already have with your

child will be deepened when you **openly collaborate** with your child using **developmentally appropriate language**. When you have practiced these routines at home and you then follow through with them in the hospital you will add to your child's sense of familiarity, trust and security. This will **reduce stress and increase positive coping** with the challenges encountered in hospital.

### Ready Steady Go. Stop!

Further pacing can be afforded to frightening treatments such as removing taping and plasters or taking medicine orally or in a cannula and taking out stitches. Children typically can **fear that the care will be painful** but also their pain will not be noticed or that the treatment will not be stopped if it is all too much. Parents/caregivers can help caring staff tune into this pacing method **'ready, steady go. stop!'** You can say **'ready, steady go'** and the nurse or parent/caregiver can begin the task. Your child can say **'stop'** at any time and the caring staff member or parent/caregiver can then pause. You can actively help your child calm a little. You can collaborate with the caring staff member as to how much of the treatment is done and how much is left to do. You will observe

your child catching their breath and self-calming a little before you need to start the care again with **'ready, steady go'**.

By doing this, your child learns that their voice can be heard **in non-urgent or non-complex nursing/medical** cares. They will feel less overwhelmed by feeling involved in their own care. Practically speaking this usually adds minimal extra time to the task at hand.

### Relaxation training

We've spoken a lot in this guide to surgery about parents/caregivers being a reliable source of soothing for your child. All of us need to learn to self-soothe sooner or later to manage life's ups and downs. Practicing relaxation techniques before coming into hospital is the best approach as new skills cannot be learned when you or your child are feeling stressed in hospital. There are many children's and teenager's **relaxation guides/guided imagery/progressive muscle relaxation/breathing guides/relaxing music/meditations/mindfulness guides** available on-line, in books or in APP stores. These strategies can help to guide to a happy

place in their imagination. They can learn to associate those images or the music with deep calming breaths. **Practice every night going to bed for at least a month to create a triggered calm reaction on hearing the relaxation guide.** This will be so valuable as a source of calm when in hospital. Relaxation methods work best when they are learned and practiced together as a family. When your child observes you using explicit techniques to self-calm they will value this skill and will be open to using them too.

### **Pain management**

Let's discuss the psychological management of pain. Your child of course will be provided with pharmacological pain relief after surgery. Anxiety, worry, fear all contributes to increased experience of pain. The physiological response to a sense of threat means the body becomes hyper-aroused and overly attuned to perceived threatening sensations. Often the mind comes up with mostly negative interpretations e.g. **'Something must be wrong, this pain is going to get worse, nothing the doctor can give me is working, they don't know what it feels like!'**



**Distraction** is therefore very important in **allowing the focus of attention move** between physical sensations thoughts and actions easily without getting stuck. When a child's trusted parent/caregiver creates calm through distraction be it **conversation, reading, playing, singing, massage or eating** etc a child can more easily follow their parent's emotional lead. This will help your child to feel calmer and to allow them to spread their focus over many sensations, thoughts and actions.

Your child will experience much sensory input throughout their post operation recovery time. But what if you both have a well-practiced hand/arm, foot/leg or head **massage routine** established which you both enjoy and which helps release those beautiful **feel good pain relief** hormones naturally? These hormones called **endorphins**

not only help your child to feel better emotionally, but they are also the body's **natural pain relief**.

When your child needs an **injection**, and if you get in there **first by massaging the other hand/arm/leg**, you are helping your child produce natural pain killing hormones. Furthermore, you are also distracting your child's brain! It is possible to provide sensory input which will compete with other painful sensations and so distract from paying sole attention to painful input. Try it yourself; have someone rub their fingernail along your right forearm and rate the pain 0=no pain 10=extremely painful. Then have someone massage your left hand/forearm while they run their fingernail up your right forearm and give this sensation a score out of 10! You will likely notice a **reduction in your pain score!**



## HONESTY IS THE BEST POLICY

### Number of days in hospital

Try to be nonspecific about the number of days you need to be in hospital to avoid frustration, worry and mistrust. Instead focus on function and what needs to be achieved first before discharge can occur e.g. **'When you are walking well, chest drains are out, you are eating well and you have no temperature then we can all go home.'**

### Staying connected with family and friends

Don't be afraid to discuss home and people there as it can be an isolating experience for some children to be the only child in their family needing a cardiac surgery. They will miss their siblings, pets, friends and relatives. It is important to **keep the emotional connection alive** between your child in hospital and others at home. Some children can become quite hopeless and depressed believing that they are stuck in hospital for what seems like forever. Keep video calls going, encourage text messages back and forth, have siblings lend each other toys/games/equipment back and forth from the

hospital. Co-write a text or letter to friends or school giving updates. Since the Covid pandemic there have been changing visiting restrictions for siblings and others family members. Siblings and family members have come to the car park and while talking on the phone waved to the child at the window! Even though siblings are not allowed in ICU they can come to visit the hospital, go to the canteen etc and share a little in the family experience of surgery. The integration of the two realities creates a shared experience even when separated.

### How do you want to do this?

Try to **avoid falsely investing** in discussions about whether or not your child will take the medicine/get a cannula but instead **discuss how** they will take their medicine/cannula. When taking medicines have a plan for drinks and treats before and after to minimise the taste. Agree the order in which treatments can be done. Agree which parts of the treatment can be done by the doctor, by the child and by the parent/caregiver.

## Disguise the taste

Talk with your child about the need for a plan to take medicine that they do not like. When taking bitter tasting medicines **engage your child's taste buds in another pleasant taste first** it is likely that the full taste of the medicine will not be detected by the tongue. Consider sucking a chocolate lolly-pop before taking the medicine so that there is a nice thick protective coat of chocolate on the tongue's taste buds and the medicine is less likely to be tasted. Practice this at home.

## Get to Yes

If your child still resists taking oral medicines in hospital, try to calm and **slow everything down**. Ask the nurse to leave the medicines with you if possible, talk less and move less. Allow your child to be calmed and soothed because then they are more able to discriminate and understand this singular task. **Be patient** and let your child know that you understand this is upsetting for them, but you are happy to take things slowly and when they are ready.

Quietly get the **'magic bag'** with all the reward treats in view so that the attractive part of taking medicine is available. Get all the drinks, sweets etc ready to help wash down the medicine. If there is more than one medicine to take, let your child choose which one they want first. Move all the others away to another table to **reduce the sense of threat**. Negotiate what your child can do after the first medicine for 5/10 minutes before they choose their next medicine e.g. play with their toys or watch their iPad etc. This can also help to avoid too many medicines being given in quick succession and being vomited back up which is upsetting and worrying for everyone involved.





In hospital you may help your child understand by repeating words or phrases and using gestures e.g. **‘How about you walk from here to the chair (point) or from here to the door (point), you choose’**. Provide choices where **either answer is good**. Showing repeatedly, e.g. **‘which medicine do you want to take first the pink one or the white one (hold them up, one in each hand to be seen clearly)’**. **‘Which arm will we take a blood pressure reading?’** Point to the blood pressure band, point to your arm, then use a gesture for finished.

### Emotionally tune into each other

At home you can make a game out of guessing facial expressions illustrating different feelings. This helps teach your child to use a feeling vocabulary and to communicate safety with invested caregivers. Knowing that you are there as emotional coach to help them cope is secure making. **‘I’m not sure how you are feeling about getting a blood test is it sad, happy or I don’t mind’**. Always check in with how your child feels after a treatment is done. This helps to emphasis how **each experience is temporary and manageable**. You can use hand gestures e.g. thumbs up, thumbs down or in

between. You could print off a page (or have it on your phone) of facial expression drawings and ask your child to point to the one they feel now and how they feel 10 minutes later and an hour later.

Plan together how you will sit together in close physical contact e.g. on your lap (similar to when you hold your child on your lap for a vaccination) or snuggled in beside your child in their bed. Staying close will mean that your child knows that you understand the treatment task, you agree with it and you will participate in what is happening to ensure your child can cope. **Play this scenario out at home**. Your child will feel that their perspective is understood by you and that your offered soothing strategy matches the challenge. They are far less likely to feel abandoned on the bed and left to a treatment with a caring staff member they may not have worked with before and that they do not trust yet. Make sure you are in position before you let the caring staff member know you are ready.

## Staying still

Practice specifically helping your child to recognise that staying still will make the procedure **'Go Fast'**. Work on practicing **'freezing'**, or **'staying still'**. Act out and count out loud how long it will take to get a job done **'if we wiggle it will take a long, long time but if we stay still it will be quick!'**

Let your child see the choice they have regarding how they complete a care task and how long it takes. Have a parent/caregiver play with medical equipment and act out receiving an injection or cannula. Wiggle and pull away while counting out loud. Discuss how very long you counted for and how you want to help them be quicker, **'quicker is better'**. Then play act at getting an injection but this time say **'freeze, I want a quick injection with a little ouch'** and start counting to show how short lived the event will be when you stay still.

The choice of agreeing to or rejecting a care task such as an injection i.e. **'yes or no'** is not possible and is therefore a fallacy. Energy should not be invested in this discussion. **'How we get a job done quickly'** with a **'Little ouch and not a big ouch'** is within you and your child's control and so this is worth investing in. Also **'when the cannula is**

**done then you can have a treat/relax/get a star on the chart'**.

## Team approach

Show how stress management strategies work best as part of a team approach. Everyone in the team shares the goal of making a treatment less stressful. Prepare choices for your child and then consider asking your child;

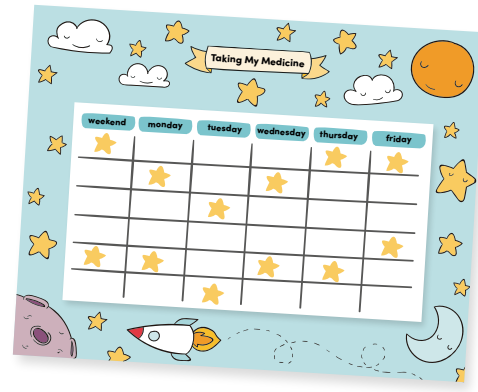
- **'What can I/you/ the nurse do to help, when you need e.g. a blood test?'**
- **'Which parent/caregiver do you want to help you?'**
- **'Will I stay close or move away?'**
- **'Do you want me to help you get a quick blood test by helping you to stay still?'**
- **'Choose which medicine to take first?'**
- **'Do you want me to tell the nurse to pause? Do you want to give me a signal e.g. hand up for stop or do you want to say 'stop?''**
- **'Do you want the doctor to tell me what is needed next and then I can tell you?'**
- **'What do you want to do after the job is done?'**
- **'What kinds of treats or rewards will you deserve after every hard job you do.'**

## Star charts

Star Charts may seem like a simple tool but if used well they can facilitate positive coping in hospital. Star charts illustrate the agreement or contract that **WHEN** we do a task first **THEN** we get to do something pleasant/receive some treat. Download some themed star charts from the Internet that may be attractive to your child e.g. Paw Patrol or Peppa star charts. Here are some ways to use star charts to help your child negotiate the challenges in hospital.

Practice using star charts at home to indicate the expectation when you do this then this will happen. E.g. **‘WHEN you brush your teeth THEN we can read your bedtime story’** or **‘when you finish your homework then you can watch TV’**.

Believe it or not even some **teenagers** have reported that they appreciate the use of a visual chart of their achievements and successes in hospital. They like staff and family to notice and acknowledge what they have achieved.



Even before coming to hospital discuss what effort gets a star in hospital e.g. taking medicine, going for walks with chest drains and getting a cannula etc. At the end of each day in hospital have a reward planned for all the effort of the day.

You can **pack presents** to come to hospital with you or maybe the reward is an experience e.g. watching their favourite show, playing a particular game or singing a favourite victory or happy song!

Rewards reinforce that your **child is good and deserves good things**. While you are in no doubt about this fact your child will need reassurance in hospital. By regularly referencing their efforts as chronicled on the star charts throughout the day you can help to redress this balance.

## Review your day in hospital

At the end of each day use the star chart as an opportunity to help your child claim the achievements and successes of the day. So even if your child was crying, wriggling and objecting to certain nursing cares during the day by focusing on the fact that they still completed them can be best emphasised at the end of the day when the heightened emotions have passed.

By calmly highlighting the positives you can move on to plan together for an even 'calmer or 'quicker' time. Remember the 3 stress systems? When calm both you and your child have a greater capacity to think more creatively and with increased problem solving. When calmer they will have an increased capacity to recognize your motivation and that of the caring cardiac team. With your support you can help your child to plan for a less stressful time the next time. This will help build their confidence in themselves and their ability to manage these particular nursing cares the next time.

E.g. **The nurse wanted to give you the medicine to help you get stronger. I want you to get stronger, I want you to go home too, so I helped you get your medicine. 'You**

**thought the nurse was being mean and trying to hurt you and so you were scared', the nurse was helping us get you stronger and ready to go home'. 'Well done. You are helping yourself get stronger after your operation and to then go home. That was hard work today! I'm so proud of you. What can I do to help more the next time, what can you do to help and what can the nurse/doctor do to help?'**

## Immediate rewards reduce the time exposed to upset

Some days in hospital can be one challenge after another in quick succession. Immediate rewards particularly for the younger age group can be both an acknowledgment of the challenge and a positive distraction after an upsetting event. The older child might earn a euro on a gift card for every treatment they achieve. Get them to keep a tally after each treatment. Immediate rewards can provide reassurance that despite upset everyone still considers the child as good and their efforts as appreciated. By giving a small novel immediate reward the challenge can end on a positive note.

Shop together for small reward so your child knows what to look forward to. Keep the treats in a special ‘**magic bag**’. By encouraging your child to move their attention on to the toy or sweets they are no longer thinking or looking at the challenging nursing care. In this way you are helping your child to shorten the amount of time they are exposed to a stressful event. You are helping them recover and quicker. Immediate rewards are a helpful way of letting your child know in words and actions that the challenge is over.

### Create a home away from home

When you are in ICU and the CHC create as much familiarity in these unfamiliar places as possible. Once you have washed teddies, bed linen and clothes they are all welcome in hospital. Having familiar objects, sounds and smells around can be reassuring. Decorate the bed with familiar toys and bring photos of loved family members and pets. Bring music toys for babies. Download favourite music and films on a phone/tablet to be enjoyed passively while they are feeling low in energy post-op. This can all aide a better sense of rest and relaxation and counteract other hospital sights and

sounds that may well trigger anxiety. It is particularly soothing when you need to leave ICU.



## Reading to your child

Reading a favourite book to your conscious, semi-conscious or unconscious child has been shown to reduce stress and helps to orient children when in hospital and especially in ICU. As you read your continuous familiar voice will help your child tune into you and to tune out of the unfamiliar noises and voices in ICU.



## A SPECIAL MENTION FOR SIBLINGS

**You will want to emotionally protect all your children during this surgical journey.** You might like to think about this surgical chapter in your family's life and how you want it to be experienced by all your children. This should help orient you to what you want to achieve at this time as a parent/caregiver.

Of course you want all your children to feel loved and valued but how will they experience this during a hospital stay? You will need to forecast for absence and disruption to normal family life. A parent's/caregiver's absence needs to represent protection for your child with a heart condition at a time of extraordinary challenge. Your absence does not mean that your other children are any less valued. It is important to speak about this explicitly to avoid siblings drawing a negative conclusion. You will need to plan for when and how you will reconnect with all your children. You will need to forecast for failed, frustrated reconnections as these are a possibility. Emotionally coach your children through how

they may feel at those times and ensure they understand that sometimes things will not go to plan, but this does not reflect lack of commitment to them.

Involve all your family in the medical play practice.

Siblings often feel surplus to the task around the time of surgery. Your children will **feel more included** and protective towards their sibling. By exposing your children to the medical play and protective calming routines for treatments in hospital you can **increase their empathy for their sibling**. They will better understand why their sibling will always need at least one if not both caring adults with them in hospital.

Siblings can be emotionally tuned in and they may not want to cause a fuss or **bother their already stressed parents/caregivers**. Tell them that their needs are important too. Tell them that you will make time for them but you need them to tell you what is on their mind. Prepare to deal with **a sibling's normal everyday upsets** such as a friend excluding them. Although this may seem trivial next to cardiac surgery it is however that child's crisis which may well need your attention.

You will want to ensure that all your children have the **correct information** regarding separation and the surgery experience ahead. It is worth checking out their worries as their **imagination may be worse than the reality**. Older siblings often fear the pain of surgery and the risk of death for their sibling. They may look up cardiac surgery on the internet and have been exposed to distressing images. They need you to these worries by make sure there is space to talk about them.

Even when the sibling's carers are managing to keep the siblings distracted and busy this is unrealistic on a 24/7 basis. Ensure there is one caring adult identified as a good person to talk with when upset. Tell schools and crèches the situation and **ask someone to check in emotionally** with your child during the hospitalisation. It is emotionally protective to forecast for feelings of loneliness due to separation. Discuss how you both feel the same emotions when separated from each other. When separated ask about upset **'you sound upset what are you worried about?'** This should help them to keep abreast of their emotional journey and be less likely to become overwhelmed. Tears are a normal communication when separated for surgery.

Tell them you wish there was a way that you could be all together all the time, but the hospital has rules about visiting so that the risk of colds and germs are reduced for the kids in hospital.

Younger children will typically find it challenging to understand the separation and the need for new carers. You may choose to visit your children regularly, if it is possible, or they may come to stay if you have accommodation in the Ronald McDonald house. This will become more important if the hospital stay goes on longer than a week. Parents/caregivers often wonder if it is traumatising to visit their children when there are tearful goodbyes. Your reconnection with each other affords your children **continuity of emotional care** and avoids the buildup of unmanaged emotions within the parent-child relationship. Do aim for regular visits and ask them how they want to use this precious time together. Ensure each child has some alone time with you. Plan your goodbyes together and anticipate upset. Tell them **'I miss you too, I wish I didn't have to go too, (agree) how many more hugs/kisses/games will we have before I go? What treat can I get you for letting me go even though you are sad?'**

Plan for special rituals of connection by text, phone/video call. Plan emojis that have a special meaning to each other to help **feel closer**. Put a photo of you and your child by their bed. Ensure that the adults minding your children **allow them to call you** on their emotional timetable. Explain to your children that you will only be able to answer your phone if there is not anyone else in the room. You will call them back. Give your child an important **task of family oracle**. This will help them feel more emotionally connected e.g. **'my sister sat up today'**. Finally, encourage siblings to send some of their games and books for the child in hospital to **express their love** and empathy.





## RECOVERY AT HOME

The surgical journey will continue at home. Your child will continue to recover physically and emotionally. They may remain very **alert to every physical sensation**. You can help by talking about what they are physically feeling and letting them know those sensations are normal.

**Sleep** can be disturbed due to their experience of the hospital timetable and/or **bad dreams**. Using familiar bedtime routines along with music or white noise can help settle an over active mind. Talking and playing out hospital experiences in the day can reduce bad dreams. Try talking and drawing the bad dream to help make sense of their worries.

Get back to family **daily routines** as this will help your child feel safe. By proposing familiar routines you can help your child feel confident in their ability to get back to a normal life. Talking about the day's plans will help your child feel that life is predictable.

**Normal touch**, such as hugs, dressing and bathing can feel threatening after surgery. Help your child to tell the difference between threatening and non-threatening touch by slowing down your movements around them, letting them do as much dressing/washing as possible and reducing overall expectations until such time as they recover.

**Food and eating** can be disturbed. Offer your child healthy choices, try to make meal times more casual and reduce your expectations for a perfect diet for a while.

Children may **regress** i.e. use baby talk, wet the bed or ask for more help than is needed. This can be a sign of insecurity and that life is currently too demanding. Try to minimise demands until they feel secure again.

Overall **emotional recovery** is helped by medical play as your child tries to make sense of their hospital experiences. Play can be solitary or shared. You may gain insight into their felt experiences by noticing the mood of the game, e.g. frightened, proud etc. Sometimes the overall hospital experience can be confusing for children. Once you are

home and away from the stress of surgery there is now an opportunity to continue working with your child to correct some of the misunderstandings or clarify some of the experiences while in hospital.

Play Therapy can help support recovery from surgery. Encourage older children to **draw or write about hospital** to emotionally process this significant life event. It is tempting to try to forget about surgery. If you do, you may also neglect to recognise your personal resilience and positive coping as a family. **Post Traumatic Growth** with its potential positive impact on your life is fueled by reflection. Life can have new meaning, life goals can become clearer and relationships more meaningful.

Finally, you may like to talk with other parents who have gone through cardiac surgery and to a therapist to support you and your family's recovery.

An illustration of a lighthouse on a cliff overlooking the ocean. The lighthouse is tall and cylindrical, with a red top section and a white bottom section. It has a red dome on top and a small window. The cliff is green and yellow. In the background, there are blue waves and a white sailboat with a red and orange sail. The sky is blue with white clouds.

**A very special thank you to the families whose lived experiences have contributed to, and been at the heart of this guide.**

**We hope this resource supports you on your cardiac journey.**

**Your cardiac team will be with you every step of the way.**



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