



Children's
Cancer and
Leukaemia
Group

Managing symptoms at home

Palliative care information for families



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Originally written by Alison Dowsett and the Paediatric Oncology Palliative Care Team, Cambridge University Hospitals Foundation Trust, in collaboration with the CCLG Publications Committee. This edition was reviewed and revised by the CCLG Publications Committee, comprising multiprofessional experts in the field of children's cancer.

Thank you to all those who contributed to this booklet.

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Publication of this booklet was funded by CCLG

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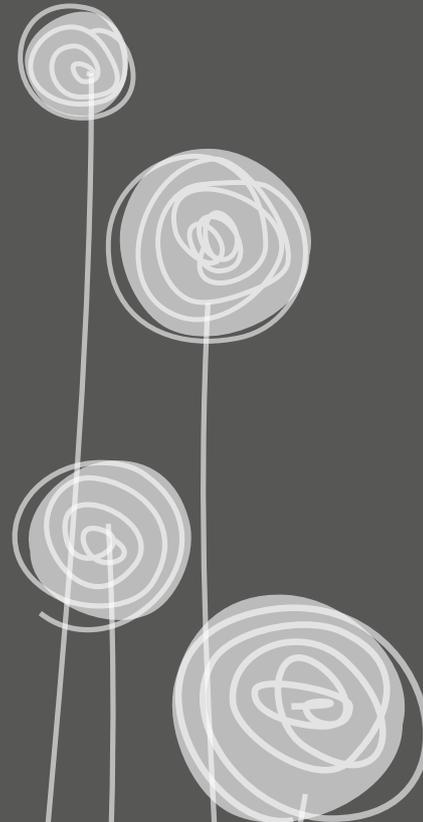
Reviewed: October 2020
Next review due: October 2023

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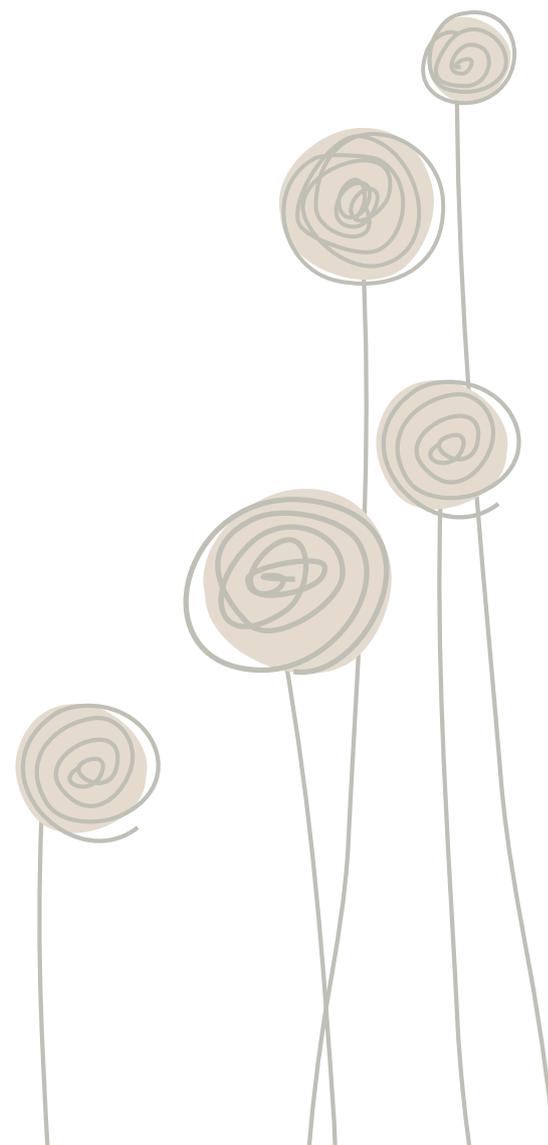
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Contents

Palliative care	5
Aims	6
Multi Disciplinary Team meeting	6
How to cope with common symptoms	7
Pain	8
Nausea and vomiting	12
Breathlessness and other breathing problems	14
Fatigue	17
Fits (seizures)	18
Constipation	20
Agitation and restlessness	22
Itching	23
Urinary problems	24
Bleeding	26
Specific issues with brain tumours	27
General care	31
Nutrition	32
Alternative and complementary therapies	33
Relaxation techniques	34
Sources of help and support	39
Useful organisations	40
Helpful local sources of support	41





Palliative care



This booklet is about 'palliative care' - the phase of treatment where cure is no longer possible – and is concerned with managing symptoms and quality of life.

It has been written to give you information about commonly occurring symptoms, their causes, available treatments and, most importantly, suggestions for simple things that you can do at home to help your child.

It also includes information on services which are available to your family, an explanation of how care and services will be organised around you and information on how you can contact these services for help and advice when you need it.

Aims

The aims of palliative care services are:

- To arrange services to meet the specific needs of your child and your whole family
- To manage symptoms promptly
- To provide care where you want it (as far as possible)
- To provide your whole family with as much support as you need

Multi Disciplinary Team meeting (MDT)

To best plan your child's care, a multidisciplinary team meeting may be arranged.

This will bring together people from different disciplines and different organisations, some of whom will already be well known to you. This meeting may include:

- Your GP
- Local community nurses
- Your outreach nurse specialist
- Your CLIC Sargent social worker
- Your hospital consultant
- A representative from your local children's hospice
- Other significant people, e.g. teachers, clergy
- You can also ask for anyone you particularly wish to be involved

At the meeting, it will be agreed who is to take the 'lead professional' role – this is the person who has particular responsibility for coordinating your child's care and making sure that communication between you and all the professionals goes smoothly. This will usually be someone who is already well known to you, for example, your local outreach nurse.

One of the lead professional's jobs is to keep in regular contact with you, so that if new symptoms develop, they can rapidly call on other members of the team to treat your child promptly. You will continue to have direct access to other professionals, for example, your GP, hospital team, and hospice.

One of the nurses who is known to you can feed back to you after the meeting. You may be able to attend the meeting. Please speak to your doctor or nurse about this.

How to cope with common symptoms

This section explains some of the more common symptoms, their causes and treatments.

It also gives you some ideas on what you can do as a parent.

Not every child will have every symptom, most will only have a few.

If your child develops one of these symptoms, this booklet should be able to answer some of your questions, until you have a chance to discuss it with your doctor or nurse.

Pain

The purpose of this section is to give you the knowledge you need to help your child: how you can recognise pain, some information about different types of pain and what you and your nurses and doctors can do to try to relieve pain.

Everyone knows what pain is, everyone has experienced pain at various times in their lives but it can be very frightening. Fear makes pain worse, so it is helpful if you can remain calm and confident as this will help your child to remain calm and feel in control.

It is quite common for a child to feel pain at this stage in their illness, but it is sometimes difficult to know if a child is in pain.

Physical pain

How do you know if your child is in pain?

Your child may be able to tell you about their pain but some children, particularly younger ones, can't really describe how they feel and you need to pick up clues from how they behave:

- They may be unable to settle to any activity or appear restless
- They may just sit still or sleep in one position and not want to move around
- They may become distressed if you carry or move them
- They may be unable to sleep properly

Remember, as parents, you know your child best and if you think your child is in pain, please tell your nurse or doctor.

What can your nurse or doctor do to help?

- They try to understand the cause and type of pain and prescribe the best medication for the type of pain your child has
- They may use different types of medication which often act better together than on their own
- They will review your child on a regular basis and will change the medication as your child's condition changes
- They will explain exactly what you should give and when

Pain tends to come in waves and it may not be possible to control pain completely, but the aim is:

- To give enough regular medication to keep your child free of pain for most of the time, and to take the edge off the waves of pain
- To give you additional medicine that you can use for the peaks of pain

What treatment can your child have?

Pain relieving medicines

There is a wide range of pain relieving medication to manage mild to moderate to severe pain – these will usually be prescribed as regular and ‘breakthrough’ doses

- **Regular medication**
 - Give it on time
 - Give it even if your child has no pain
 - Give it on time even if you have recently given a dose of ‘breakthrough’ medicine
- **‘Breakthrough’ or ‘as-required’ medication**
 - Even with regular medication, your child may still experience episodes of pain: you will be given a supply of quick-acting medication to use for these episodes
 - Encourage your child to tell you if they are uncomfortable or in pain
 - Watch out for ‘silent’ pain – moving often brings on pain, some children are too frightened to move
 - You may use breakthrough medication before any activity which you know will be painful, e.g. moving
 - Give this in addition to the regular medication
 - Keep a record of these episodes of pain and of the medication you have given and tell your nurse or doctor
- Your nurse or doctor will review how much pain relieving medication your child needs on a regular basis
- It takes a couple of days to see the effects of any increases in regular doses

Side effects of pain relieving medicines

- Constipation: morphine and its related medicines slow down the bowels – it is nearly always necessary to give additional medication for this (see page 20)
- Nausea: children may feel nauseated (sick) during the first day or two of morphine but this will usually wear off (see page 12)

- Sleepiness: your child may be a bit more sleepy when a dose of morphine is increased but this should wear off after a day or so – if they remain very sleepy, you should tell your nurse or doctor
- Itch: morphine and related medicines may cause itchy skin, this should get better within a couple of days, if it doesn't, tell your nurse or doctor: they may need to change the medication
- Urinary retention: very occasionally morphine may make it more difficult for your child to pass urine. If you are concerned please ask your nurse or doctor about this

Additional medicines

These are different types of pain. For some of them pain relieving medicines work best when combined with other medication:

- 'Bone pain' and 'soft tissue pain' (caused by a tumour in bone or muscle etc)
 - Non-steroidal anti-inflammatory medicines, e.g. Brufen, Diclofenac help by reducing inflammation and swelling
 - They should be taken regularly with or after meals or a snack
- 'Nerve pain' (caused by a tumour pressing on nerves)
 - Some anti-epileptic and anti-depressant medicines can help 'nerve pain'
 - They should be taken regularly
 - For some medicines, the dose may need to build up over a week or so
 - It may take 7-10 days for these medicines to achieve their best effect, so keep going with them
 - Steroids are sometimes prescribed to reduce swelling and pain, when a tumour is pressing on or damaging a nerve, but only for a limited time because of side effects
- 'Muscle spasms' (cramp-like pains in muscles)
 - Muscle-relaxing medicines can be prescribed for painful spasms

How can the medicines be given?

- Tablets and liquids may be easy if your child can swallow and keep them down
- Patches: some pain relieving medicines are available as a patch which goes on the skin – like a plaster – and releases the medicine gradually
- Lozenge: some pain relieving medicines are available in lozenge form which can be rubbed inside the cheek, this works quickly and can be good for peaks of pain
- 'Buccal' medicines: pain relieving medicines can also be given by syringe into the mouth inside the cheek for a quick effect. These do not need to be swallowed to be effective – they go straight into the blood stream.
- Continuous pump; pain relief can be given continuously through a subcutaneous cannula (this goes just under the skin) or may be given via your child's central line
- Suppositories can occasionally be used

What else can you do to help?

A number of physical aids and psychological techniques can work alongside medication to make your child more comfortable.

Physical aids

Pressure relieving mattress

- If your child finds it difficult to move in bed, pressure areas may become sore and add to their discomfort. Your nursing team may be able to arrange a pressure relieving mattress and a hospital bed for your home

Use of heat and cold

- Hot or cold compresses may take the edge off pain while the medicines have a chance to work

TENS Machine

- This is a small, lightweight, battery operated device with adhesive patches which gently stimulates nerve endings to block painful impulses and helps muscles to relax
- The device is operated by the child so it gives them some control

Relaxation and other techniques

Relaxation and distraction can often help pain and other symptoms; you can ask your nursing team or play specialist for more information.

- See the section on relaxation and guided imagery (page 34)
- Massage may help
- It may be possible to arrange art or music therapy

Emotional pain

Children can suffer psychologically as well as physically, this sometimes goes along with physical pain but it can happen on its own. Here are some ways in which your child may express that they are hurting:

- They may become withdrawn, tearful or inconsolable
- They may refuse to talk to anyone, or be angry at those around them
- They may be unable to concentrate
- They may complain of tiredness or bad dreams

What can be done to help?

- Allow your child opportunities to talk about their feelings
- There is a range of professionals who may be able to help - the team at your child's hospital will be able to provide further information

Nausea and vomiting

What is meant by nausea and vomiting?

- Vomiting means actually being sick
- Nausea means feeling sick. Feeling sick is a very unpleasant feeling, but it does not always end with being sick. It may not be obvious that your child is feeling sick; he or she may just be very quiet or not want to eat
- Retching is when the stomach heaves, but nothing comes up – it is also very unpleasant

Is it unusual?

No, it is common for children to feel or be sick at this stage.

Why is your child feeling sick?

There are many reasons why your child may feel sick. It may be for an obvious reason:

- Some medicines may make your child feel sick
- Coughing, especially if producing thick phlegm, may make your child retch
- Children may feel sick if they are constipated
- It may be due to the position of the tumour
- Vomiting is occasionally due to a blockage in the bowel (intestines)
- Vomiting or nausea may be due to abnormally high or low levels of certain chemicals in the blood (such as potassium, magnesium, phosphate)
- Some children feel sick with sudden movements, like travelling in a car (motion sickness)
- Sometimes the cause is unknown

Can you do anything to help?

There are a number of things you can do to help.

- A change of position may help
- Fresh air often helps – sitting by an open window or near a fan
- Your child will feel more sick if he or she is anxious; you may be able to help by distraction, such as watching a favourite film or playing a game, or using some of the suggestions in the relaxation and guided imagery section (page 34)
- Cooking smells can make nausea worse – try to keep your child away from them
- The sight of a large meal can also make nausea worse: try serving smaller meals or snacks; these look less daunting on a small plate. It may help your child if they can eat on their own.

What can your nurse or doctor do to help?

- Your nurse or doctor will try to work out what is causing the sickness but it is not always possible to find a cause
- Sickness can still be treated even if the cause cannot be found
- It may not always be able to completely stop your child from feeling sick or being sick. But it should be possible to reduce the number of times your child is sick and to reduce the feeling of sickness
- If your child is very anxious, your doctor may ask the play therapist to work with them

What treatment can your child have?

- There are many anti-sickness medicines which work in different ways
- If your child has had chemotherapy or radiotherapy, he or she may have had some anti-sickness medicines, but these medicines are often less effective when the sickness is not caused by chemotherapy
- If your child is constipated, this may be causing sickness or making it worse. It is important to treat the constipation (see page 20)
- If your child has a blocked bowel, medicines can be given to reduce the sickness and to reduce the amount of fluid in the stomach
- If medicine is causing the sickness, your doctor may be able to change it
- Morphine may make your child feel sick for a few days after starting it: this can be controlled with medicine but the sickness effect will wear off after a few days
- If movement causes your child to feel sick, travel bands may help

How do you give the different medicines?

- Anti-sickness medicines come in different forms
- Tablets and liquids may be easy if your child can swallow and keep them down
- Suppositories can be used even if a child is vomiting a lot, but they don't suit everyone
- Continuous pump: anti-sickness medicines can be given continuously via a subcutaneous cannula (this goes just under the skin) or may be given via your child's central line
- Patches: some medicines are available as a patch which goes on the skin

Breathlessness and other breathing problems

What is meant by breathlessness?

- Breathlessness is a common experience, for example, after running most people feel the need to breathe more quickly and more deeply than normal. In addition, children who are breathless because of disease may find it quite difficult to breathe and struggle to get breaths in and out.
- Children who are breathless are often anxious as the experience can be frightening: they may worry that they won't be able to breathe or that they may choke
- It is common for breathless children to have episodes where their symptoms appear to 'spiral out of control', although, in between, their symptoms are more manageable
- It is natural for you to feel scared and anxious when your child is breathless

Why is your child feeling breathless?

There are many reasons why your child may feel breathless.

- Your child may have secondary tumours in the lungs or pressing against the airways
- He/she may have a lot of fluid around the outside of the lung which restricts the lung (pleural effusion)
- Your child may be anaemic
- He/she may have a chest infection

These additional problems may make breathlessness worse in children with lung secondaries or pleural effusion.

Whatever the cause, your child may experience 'attacks' of severe breathlessness: these are usually brought on, or made worse, by anxiety.

What can your nurse or doctor do to help?

- They may be able to treat any factors which are making the symptom worse (e.g. anaemia)
- They can prescribe medication to reduce the sensation of breathlessness
- They can arrange for you and your child to learn relaxation techniques which can also help to reduce the feeling of breathlessness: this may be with the play therapist, psychologist and/or physiotherapist

What treatment can your child have?

- Your nurse or doctor will try to treat any factors which may be making the symptom worse
- Morphine is well known as a pain relieving medicine, but in quite low doses it is often very effective for breathlessness
- Mild sedatives may help your child to relax and improve their breathlessness
- If there are lumps pressing on the airway, the swelling can sometimes be reduced with steroids, but steroids will not make much difference to most children
- Some children find oxygen helps their breathlessness: if it helps, your GP will be able to order it for them
- Antibiotics are not often helpful, unless there is clear evidence of a chest infection

Can you do anything to help?

There are a number of things you can do; find which approach suits your child best.

- Reassurance is very important as anxiety plays such a big part in breathlessness: try to be calm and reassuring, even if you are feeling very scared yourself
- Your child may feel less breathless if he/she can feel 'fresh air' on his/her face: an open window or a fan (electric or hand-held) is often effective
- Many children find it easier to breathe in a particular position: this may be sitting up and leaning forward (e.g. over a table or cushion) or lying on one particular side if there is fluid around the lung
- If your child has been taught breathing exercises by the physiotherapists (e.g. breathing out slowly through pursed lips), encourage him/her to do this
- Relaxation techniques or play therapy can help at home (ask your play therapist about this)
- If there is a noticeable difference in your child's breathing you should contact your nurse or doctor for advice

Cough

What is a cough?

- A cough is the body's attempt to remove something irritating from the airway or lungs
- A 'fruity' or 'productive' cough is an attempt to shift phlegm or secretions in the throat or lower down
- A 'dry' cough is often caused by irritation in the airways

What treatment can your child have?

- At this stage in your child's disease, most coughs do not respond to antibiotics or asthma-type medications
- For dry coughs, simple linctus is often effective. Using a humidifier to increase the moisture in the air may also help.
- Codeine and morphine are well known as pain relieving medicines, but they are also very effective at suppressing dry irritating coughs
- Hyoscine patches will reduce excess secretions

Noisy and irregular breathing

- Your child's breathing may become noisy and 'bubbly' if they become unable to swallow all their saliva (secretions), this is most likely in the last few days or hours of life
- Your child will not usually be aware of this, although it may be distressing for you to watch
- Breathing often becomes irregular and infrequent in the last few hours of life – this should not be distressing for your child

What treatment can your child have?

- Your doctor can prescribe medication to reduce secretions and make breathing less 'bubbly'
- Changing your child's position in bed may help to reduce secretions and the noise associated with them

Fatigue

It is quite common for children to feel very tired or exhausted at this stage in their illness. They may spend more time sleeping or curled up on the sofa and may not feel up to their usual activities.

What can you do to help?

- For many children, tiredness is not distressing
- During this time, it may be helpful to maintain a day-night routine; for example, sleeping in bed at night but dozing on the sofa during the day – this will help your child to feel they are still in the centre of things
- Many families find it helpful to adapt their routine around the child
- If your child is not sleeping well at night, discuss it with your nurse or doctor – relaxation techniques or night sedation may be helpful

Fits (seizures)

Your child may have fits at diagnosis, or following initial surgery. They may also occur during the palliative phase. Seeing your child having a fit can be a frightening experience but in most cases it only lasts a few minutes and your child will not be aware of it. There is medication which you can give to your child in order to stop fits and this is usually effective. Sometimes, more than one medication may be necessary and occasionally, it may not be possible to stop all fits completely.

What is a fit?

Fits occur when electrical activity builds up in the brain in an unusual or irregular pattern. There are different types of fits. The most common symptoms you may see if your child is having a fit are:

- A vacant blank look, unresponsive to speech
- Loss of consciousness
- Uncontrollable movements, such as lip smacking, eye twitching, and limb jerking
- Incontinence

Your child may be quite sleepy for a period of time after a fit, particularly if it was a long fit.

What to do if your child has a fit:

A fit can be very frightening to watch, but your child will not be in pain and will not remember what has happened. If your child has a fit the most important thing is to make sure they are in a safe place. Most fits do not last for more than a few minutes.

- Move anything that may injure your child
- Do not restrain your child
- Do not put anything in your child's mouth
- Turn your child's head to the side if possible
- If it is the first time they have had a fit, contact your nurse or doctor for advice and reassurance – if the fit lasts longer than 10 minutes they may advise you to give medication
- If your child has had fits before, you may have medication to give to stop the fit – follow the instructions with the medication and contact your nursing or medical team if the fit lasts longer than usual

What can your nurse or doctor do to help?

- They can prescribe medication to give when your child has a fit
- They can also prescribe regular medication to prevent or reduce the number of fits – this is usually given by mouth, but can also be given through a continuous subcutaneous pump if your child is unable to take oral medication

Constipation

What is constipation?

- Constipation is a common symptom in children receiving palliative care
- They may produce smaller, harder poo than usual and they may go to the toilet less often than before
- Sometimes a child will strain to pass a hard poo or be unable to have a poo in spite of feeling the need

Constipation often produces other symptoms

- A bloated feeling
- Crampy abdominal pain
- Nausea and vomiting
- Poor appetite
- General tiredness

Why is your child constipated?

- Some children may already have a problem with constipation before the present illness
- If your child's tumour is in their abdomen, pelvis or bladder, it may press on the bowel
- Your child may become weak or less mobile, so their bowels may not work as well
- Your child may be unable to eat or drink enough as their disease advances
- Some essential medication causes constipation

What can you do to help?

- Encourage fluids, especially water or fruit juice, although your child may become increasingly unable to drink lots
- If your child is still eating, foods high in fibre may help (e.g. fruit, vegetables, baked beans, wholemeal bread), but you should expect your child to eat less and less as time goes by

What medicines can you give?

There are different sorts of medication which work in different ways. Most children require a combination of different medications. The aim is to get a regular bowel habit, so try to give doses regularly.

- Softeners work by increasing the amount of fluid in the stool – this makes them softer and easier to pass
- Stimulants work by increasing the contractions along the bowel
- Sometimes, a child can be helped to have a poo with a suppository or an enema

Agitation and restlessness

What is agitation?

Agitation is restless moving, shouting, twitching or jerking of the body.

It can be caused by a number of things which include:

- Physical problems such as pain, constipation or an infection
- Psychological issues such as anxiety or bad dreams
- Chemical changes in the body that affect the brain and nerves

What can you do?

- If you feel your child is in pain then a dose of their breakthrough medication may help to settle them (see page 9)
- If your child is able to, then it may be helpful to let them talk about what is on their mind in case the cause of the agitation is psychological
- If the agitation comes on suddenly and is severe then you can give a dose of buccal midazolam. Please contact your nurse or doctor if you think this is necessary.
- Agitation is quite common during the last few days and it is difficult to watch, but it is worth remembering that the involuntary movements or sounds that your child makes are not normally painful or distressing for them

What can your nurse or doctor do to help?

- If your nurse or doctor is able to find a physical cause for the agitation then they can help you to treat your child so that the physical symptom is improved
- They can give medication to reduce anxiety – by mouth or through a continuous subcutaneous infusion

Itching

Causes

- Some medicines
- Dry skin
- Liver and kidney disease
- Some tumours
- Itching is made worse by hot, dry air
- Morphine can occasionally cause itching

What you can do to help?

- A bath or shower may help
- Encourage your child to wear loose, cool, comfortable clothing (cotton clothes/cotton bed linen)
- Try turning down the central heating
- Try to moisten the air – a bowl of water near the radiator

What can your nurse or doctor do to help?

- Your doctor can prescribe various lotions or creams to soothe the skin
- They can prescribe a number of different medications to relieve itching
- They may be able to stop or change medicines which cause itching

Urinary problems

Reduction in urine output

You may notice your child is having difficulty passing urine or stops altogether.

Causes

- The kidneys continue to make urine but the bladder doesn't empty - 'retention'
 - Some medicines can interfere with bladder function
 - Constipation
 - Tumour pressing on the bladder or on the spinal cord
- The kidneys don't make enough urine
 - This can be due to a tumour pressing on the kidneys
 - During the last few days, the kidneys often shut down - this is a natural process and does not need treatment

What can you do?

- Tell your nurse or doctor - they can assess whether the bladder is blocked or if it is the kidneys not working so well
- Warm baths and running water may help if there is retention

What can your nurse or doctor do to help?

- They can treat constipation or stop medicines which interfere with the bladder
- They can give medicines to ease the discomfort of a full bladder if there is retention
- They may discuss the pros and cons of putting a 'catheter' (a tube) into the bladder - this may relieve retention but it is an uncomfortable procedure

Incontinence

Older children may experience problems with bladder control.

Causes

- Constipation (see page 20)
- Immobility – difficulty moving about or getting to the toilet
- If your child is unconscious

What do you notice?

- Your child may not get to the toilet on time
- He/she may wet the bed
- He/she may seem unaware of the need to pass urine

What can you do?

- Ask your nurse about pads, mattress covers, a commode etc.
- Regular toileting if possible
- Reassure your child that it is not their fault
- Applying a barrier cream may help to protect your child's skin from urine

What can your nurse or doctor do?

- Treat constipation or pain
- Arrange equipment such as a downstairs commode, etc.
- Help with lifting

Bleeding

As tumours or leukaemia advance, they can occasionally cause bleeding in different parts of the body:

- This can vary from bruising to the appearance of large amounts of blood: your child may cough up or vomit blood, have a large or prolonged nosebleed, or produce blood in their poo
- A large bleed is frightening to see, but is usually painless. It is important to reassure your child.
- It is usually possible to identify which children are most likely to experience this and to warn you in advance that this may happen
- Bleeding may be caused by a tumour pressing on a large blood vessel or a low platelet count, but it is not usually helpful to check blood counts at this stage, it is more important to treat symptoms as they arise

What you can do

- Keep a supply of dark coloured towels and blankets: these will camouflage blood and look less frightening for you and your child
- If your child has a large bleed, contact your nurse or doctor, then give buccal midazolam and/or diamorphine. You can repeat this every 10 minutes.
- If your child develops excessive bruising, a purple skin rash (petichia) or bleeding from the nose or gums, contact your doctor or nurse for advice

Specific issues with brain tumours

This section deals with the symptoms that children with brain tumours or brain metastases may experience during this phase of care and how they can be managed. Some of the symptoms that your child may experience are not specific to brain tumours and these can be found in the earlier parts of the booklet. Brain tumours can cause a variety of symptoms depending on which part of the brain is affected: no child will have all these problems.

Raised pressure in the brain

Brain tumours can cause raised pressure by:

- Squashing the normal structures of the brain which may swell up as a result
- Or by obstructing the normal fluid channels in the brain
- If your child has a shunt, this may become blocked, and cause the pressure to go up

How do you know if your child has raised pressure?

- This will usually cause a mixture of symptoms: typically, headache, vomiting (may be morning only, often still be able to eat) and excessive sleepiness
- Sometimes, raised pressure also leads to double vision

What can you do?

- Give anti-sickness medication (see page 12)
- Give pain relieving medication for headache
- Tell your nurse or doctor

What can your nurse or doctor do to help?

This will depend on the stage of the disease:

- If your child has a shunt, it may need to be checked for blockage and repair
- Symptom control: it may not be possible to reduce the pressure, but the symptoms can be improved with medication to keep your child comfortable (for example, to control headaches and vomiting)

Dexamethasone

- Dexamethasone is a steroid which can reduce swelling in tissues surrounding the tumour. It does not have an effect on the tumour but can reduce the symptoms of raised pressure.
- The benefits are only temporary, so it cannot be used continuously
- It can be given for a few days to cover a special event
- It has quite marked side-effects, but they are short lived if it is only taken for a few days at a time

Side effects of dexamethasone

- Stomach irritation and heartburn: an antacid can be prescribed
- Constant hunger, weight gain and water retention: try frequent small portions
- Mood changes: irritability, moodiness, depression, hyperactivity
- Disturbance to sleep: mild exercise in the evening may help, if your child is able. Try giving the last dose at supper time.
- Skin problems: acne, stretch marks and hairiness can develop if steroids are taken for a longer time
- Self image: weight gain and skin problems may affect your child's appearance

Nausea and vomiting

- In a child with a brain tumour, vomiting may be a sign of raised pressure: especially if your child vomits mainly in the morning, or vomits but continues to eat - please tell your nurse or doctor
- Medication can be given by mouth but also by subcutaneous pump if your child can't take oral medication (see page 12)

Fits

For more information about fits (seizures) see page 18.

Loss of physical functions

The brain controls many functions such as speech and swallowing, vision, balance and walking etc. These controls are in different parts of the brain, so the effects of the tumour will depend on which part of the brain is affected.

Swallowing

Signs of difficulty:

- Coughing or choking during or after eating or drinking
- Pools of fluid or pockets of food in mouth, drooling
- Your child may be afraid to eat and drink or avoid certain types or textures of food or drink
- Frequent chest infections

What can you do to help?

- You can try soft foods, pureed food or thickening food
- Offer small portions more often

What can your nurse or doctor do to help?

- A naso-gastric tube may help with medicines or fluids
- They can give medicines to reduce secretions

Speech

Signs of difficulty:

- Slurred speech, speaking in a whisper
- Difficulty in finding or saying the right word

Ways to help:

- Be patient, allow time for your child to speak
- You may find communication aids helpful, for example, a picture board of common needs

Mobility and balance

Signs of difficulty:

- Your child may drag one leg when walking, or be unable to walk long distances, or tend to fall
- He/she may wobble when standing
- They may find it difficult to sit in a chair or on the toilet without falling

How can you help?

- You can help your child by supporting them when they walk, holding hands or an arm
- Let them walk indoors and short distances outside if they can and want to and use a wheelchair for longer distances
- You may find it helpful to use a chair with sides

How can professionals help?

- The occupational therapist will assess your child's needs for specialist aids

Vision

Your child may have long-standing vision problems following the diagnosis of their brain tumour or they may develop visual symptoms during this time.

Signs of difficulty:

- Develop a squint, complaining of double vision
- Difficulty judging distances
- Decreasing sight or loss of peripheral vision

Ways to help:

- Use a patch over one eye
- Glasses may help
- Using large print books or a magnifying glass
- Don't approach your child from behind as this may scare them
- Don't rearrange the furniture in your house at this time
- Don't complain if your child sits very close to the TV

General care

This section provides you with some advice about general care during the palliative phase of your child's treatment.

If you have any concerns or questions, you should discuss them with your child's doctor or nurse.

Nutrition

During the palliative phase of your child's illness, eating and drinking may cause you some anxiety. This section will give suggestions and ideas to help you manage your child's nutrition.

Your child may not wish to eat or drink due to the following:

- Loss of appetite
- Change of taste – likes/dislikes
- Nausea and vomiting
- Anxiety
- Difficulties with swallowing

How can you help?

- Offer food little and often – use small plates
- Let your child eat whatever they like
- Be prepared to feed your child at odd times of day or night
- Don't focus on the fact your child is not eating or drinking
- Offer ice lollies as they may be easier to manage than fluids
- Try crushing ice cubes and mixing with fruit juice
- If your child is still managing food, you can add extra calories, for example, butter and cream in mashed potato
- During the last few days, your child's body will need less and less food and drink: they will not feel hungry or thirsty, but they may get a dry mouth. You can help keep them comfortable by doing regular mouth care.

Alternative and complementary therapies

Many families ask about alternative and complementary therapies during this phase of care. There are many complementary therapies that your medical or nursing team would support you using alongside your child's prescribed treatment; many of these therapies are available free of charge from organisations such as children's hospices and other voluntary bodies.

- Some alternative therapies which you may find on the internet should be viewed with caution, particularly if they appear to claim extraordinary results
- Some alternative therapies may interact with your child's current medication. Please discuss this with your child's nurse or doctor.
- Some alternative therapies can be positively harmful (such as those that suggest extreme diets) or are very expensive
- It is important to ask your child how they feel about alternative treatments; some may feel they really do not want any more treatment of any kind

Please feel free to discuss any therapies you would like to use with your child's medical team.

Relaxation techniques

Helping your child to learn how to relax can help reduce anxiety. This can have a beneficial effect on pain and breathlessness. It is also an activity that can be done with other members of the family to relieve stress.

Muscle relaxation

Learning to relax muscles can be helpful both for pain control and nausea feelings.

The idea is that you are helping your child notice the difference between having tense muscles and relaxed muscles. They can then quickly ease tension when required.

For very young children, it can be helpful to imagine that they are a rag doll so encourage them to be all floppy. You can work through the body from arms, hands, shoulders, head, tummy, legs and feet to make them all floppy like a rag doll. Having a real rag doll or picture of one can help your child understand what they need to be doing.

For children aged 6 and over

Encourage your child to lie down and keep the room as quiet as possible. Read out the following script or ask someone with a soothing voice to record this for you. It is important that they do not over tense and hurt themselves. If this seems unsuitable for your child, guided imagery may be better and is discussed below.

- First let's start with your hands. Make a fist with your right hand. Pretend you are trying to squeeze the juice out of an orange. Hold it for three counts – one – two – three, and relax your hand.
- Now make a fist with your left hand. Squeeze the orange again hold it for three counts ...and relax. Notice that your hand is not tense but relaxed and calm.
- Now bend your right arm and left arm as if showing off your muscles ...that's great! Hold it for three: one – two – three, and relax. Notice how nice your body feels when it is relaxed.
- Now raise your eyebrows and count to three – one – two – three. Now relax your whole face.
- Now screw your nose up as if a butterfly has landed on it and you want to get it off! Hold it for one – two – three, and relax.
- Now clench your teeth together and pull a face hold it for one – two – three and relax. Notice how relaxed your face feels now.
- Now pull up your shoulders towards your ears like a tortoise going back into his shell. Hold it for three, one – two – three, and relax.
- Take a nice deep breath and try and put your shoulder blades together at the same time. Hold for one – two – three and relax.
- Now imagine that your right big toe has a piece of string on it and pull your foot towards you. Feel the tension in your thigh and hold it for one – two – three, and relax.
- Now do this with your other big toe and feel the tension in the other thigh and hold for one – two – three, and relax.
- Check that your whole body is relaxed. Enjoy the feeling of relaxation.

You can adapt the words as appropriate. Older children and teenagers may not need the descriptive examples, just the description of the part of the body to be relaxed.

You can move onto guided imagery after running through this exercise to help deepen the relaxation or use massage.

Using guided imagery

Guided imagery can be helpful to encourage a child to relax and to calm down if they are distressed or in pain. It can be used in combination with pain medication. It is also something you can do with your child that is soothing and non-invasive.

Imagery is about imagining a place or a story in the mind and focusing on this. It can be used along with muscle relaxation or on its own.

- Start by asking your child to lie down and close their eyes
- Help them to focus on keeping their breathing nice and calm. Sometimes counting helps to do this by breathing in for three and out for three.
- Ask your child what they would like to think about to help them relax, this could be a beach or a jungle or it could be your garden. To help your child focus on this place, ask them questions that may help deepen the imagery. For example, if a child enjoys thinking about the beach ask them:
 - Imagine that you are walking along the beach
 - What colours can you see? Notice all the colours of the water and the sand
 - Can you hear the gentle lap of the waves?
- Ask what can they feel – perhaps the sand in between their toes or the warm sun warming and calming their body
- Ask who is with them – maybe their family or other people that make them feel safe?
- Fill in the detail for them. You may want to add some soothing music or sounds that reflect this special place they have chosen.
- Ask them to focus on this scene and whenever they feel they need to relax they should think of this special place

Try to help your child create a really rich picture of their scene. Some children may like to create a story using their favourite places or things. For example, this story is written for a child who liked the thought of flying on a magic carpet like Aladdin. These exercises are really helpful for children over the age of six. For younger children they can still benefit from little stories especially using characters from their favourite story books or TV programmes.

- Make a picture in your mind of a flying carpet. Choose all your favourite colours to decorate it!
- Now you can get onto your flying carpet. Perhaps you are bringing along someone for the ride, someone who makes you feel safe. You can take all your favourite things with you on the carpet but you can pack up all your worries and pain into a case that you lock tightly with a padlock as they are not coming with you.
- Now you are ready for your trip. You can hear a whooshing sound and your carpet is rising into the air. As it rises you can feel a lovely gentle breeze on your face. Take a nice slow breath of fresh air as you rise further up. With each breath you feel more and more relaxed.
- Look down and you can see your suitcase getting further and further away from you: it feels so good. If you notice any other unpleasant feelings throw them off the magic carpet.
- The higher you go the better you feel. You can see all the villages below – look at what else you can see. Can you see the forest in the distance? If you would like to visit it take your magic carpet to wherever you want to go. You are floating down to a magical village where you see a golden lamp. This lamp is given to you. This lamp is very special and when opened, your favourite soothing colours slowly drift out making a gorgeous rainbow. You follow this rainbow – where is it taking you?
- You feel so light and calm. You are really enjoying this ride. You can go up into the clouds if you want. Just take a nice slow breath in and as you breathe slowly out your carpet rises higher and higher. You feel so light and free. You are completely relaxed and calm.
- When you are ready you can land wherever you want. Take a nice deep breath and breathe out slowly as you land.

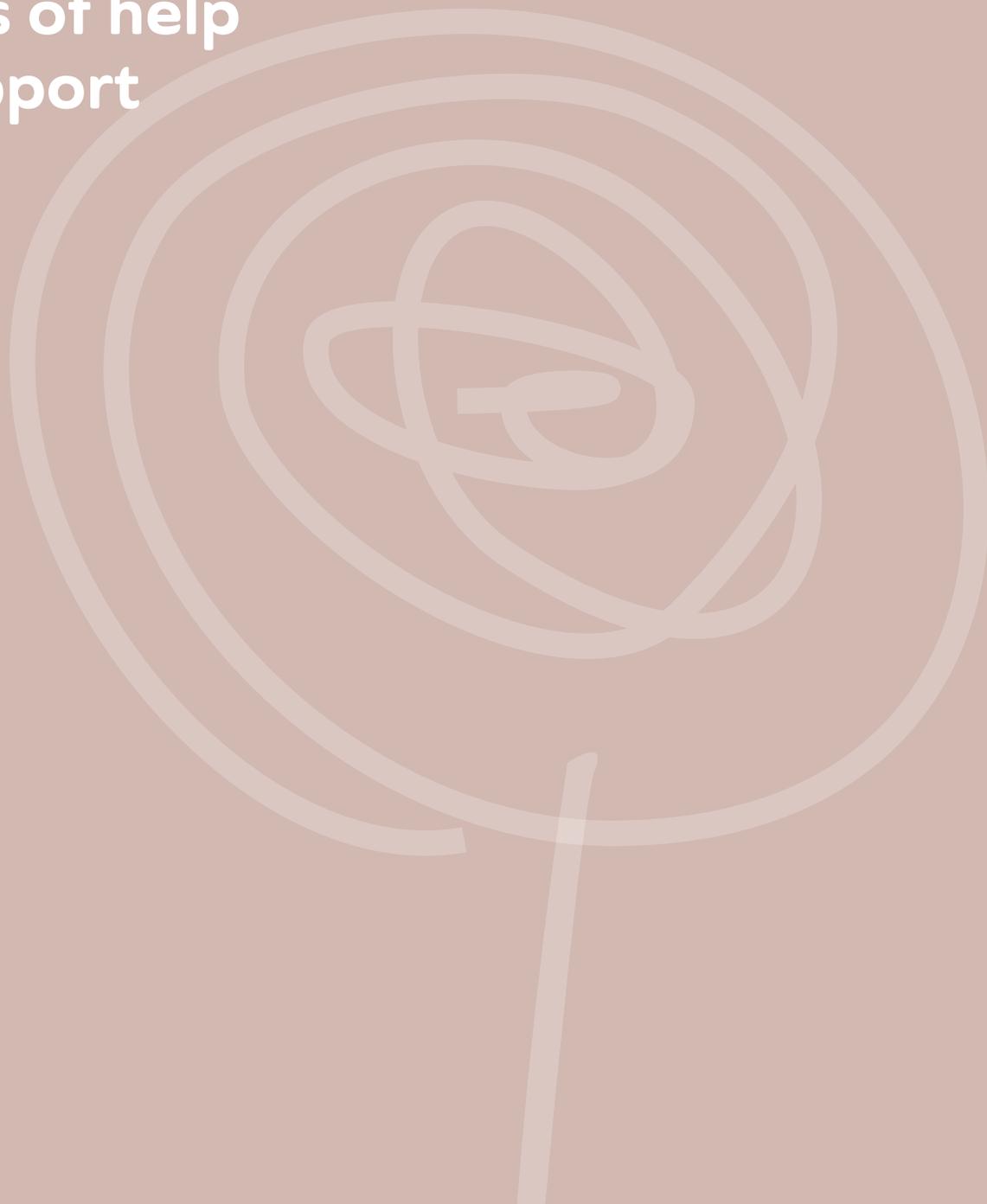
Combine this with gentle massage, if this can be tolerated, to ease tension.

You can also take images of some of your children's calming places and put them on the wall or carry them around with them.

Teenagers may still prefer to use the imagery of a special place to help them relax. They may also like to use images of soothing colours that they can imagine painting on their bodies to relieve pain. Or they can imagine turning down their pain using imaginary dimmer switches once they have relaxed. This also helps them take some control. You could also use some nice calming music to aid the relaxation process. This could be classical or sounds such as the ocean or a rainforest.

There are resources that may also be of help. For example, relaxkids.com is a website where you can order relaxation stories on CDs and in books including superheroes stories, wizard stories, and princess stories and nature stories. There are also some for teenagers. If you would like any further help about using relaxation techniques please ask your child's play specialist or clinical psychologist.

Sources of help and support



Useful organisations

Children's Cancer and Leukaemia Group (CCLG)

www.cclg.org.uk

CCLG is the professional association for those involved in the treatment and care of children with cancer in the UK and Ireland. Through a network of Principal Treatment Centres, CCLG members together with other professionals are responsible for organising cancer treatment for children in the UK and are dedicated to improving best practice and outcomes.

CCLG is also a registered charity, providing high quality, award-winning information about childhood cancer to patients and families. We also fund and support research into childhood cancer.

CLIC Sargent

www.clicsargent.org.uk

Provides practical support and advice for children and young people affected by childhood cancer and their families and offers accredited information for patients.

Macmillan Cancer Support

www.macmillan.org.uk

Helpline: 0808 808 0000

Provides practical medical and financial support to anyone who is affected by cancer.

Rainbow Trust Children's Charity

www.rainbowtrust.org.uk

Provides practical and emotional support to families who have a child with a life threatening or terminal illness.

Teenage Cancer Trust

www.teenagecancertrust.org

Supports teenagers and young adults with cancer by providing cancer services, care and support.

Together for Short Lives

www.togetherforshortlives.org.uk

Helpline: 0808 8088 100

Together for Short Lives supports all children and young people who are expected to have short lives, and their families.

They aim to be a companion to parents on their journey so they know where to go for support and have the information to help them make the right choices about their child's care. They help children and their families to access specialist children's palliative care services. Their website has a wide range of helpful information on many aspects of palliative care.

Together for Short Lives also supports all the professionals, children's palliative care services and children's hospices that deliver lifeline care to children and families across the UK.

WellChild

www.wellchild.org.uk

WellChild has UK-wide network of children's nurses, supports home adaptation projects and organises family support groups. They aim to make it possible for children with serious illness to be cared for at home with their families wherever possible.

Helpful local sources of support

Staff at the hospital where your child was treated

Staff at your child's hospital, including the CLIC Sargent Social Work team, can provide advice about the services available locally that may be able to help or support you.

Your general practitioner (GP)

Your GP will be able to provide advice about the services available locally that may be able to help or support you. This may include information about support groups, and organisations that offer other support, including practical, emotional and financial help.

Your local children's hospice service

Children's hospice services aim to meet the physical, emotional, social and spiritual needs of children, young people and their families. Care is provided by a multi-disciplinary team of specialist staff, all working closely together to ensure seamless support to the entire family (including siblings and grandparents).

Children's hospices provide a wide range of support, which may vary from hospice to hospice, including:

- Telephone support
- Practical help, advice and information
- Specialist short break care
- Specialist therapies, including physiotherapy, complementary therapies, play and music therapy
- 24 hour access to emergency care
- 24 hour end of life care
- Information, support and training for parent and carers

Children's hospice services can deliver this care in a child and family-friendly purpose built building and/or in the family's own home (commonly termed 'hospice at home').

For more information about the work of children's hospices or to find your nearest service, visit the Hospice UK website, www.hospiceuk.org, or the Together for Short Lives website, www.togetherforshortlives.org.uk, or call their Together for Families Helpline on 0808 8088 100.

Notes



We hope that this booklet has been helpful.

If you have any questions as a result of reading it, please don't hesitate to contact your nurse or doctor.



Children's
Cancer and
Leukaemia
Group

Children's Cancer and Leukaemia Group is a leading children's cancer charity and the UK and Ireland's professional association for those involved in the treatment and care of children with cancer. Each week in the UK and Ireland, more than 30 children are diagnosed with cancer. Two out of ten children will not survive their disease.

We bring together childhood cancer professionals to ensure all children receive the best possible treatment and care. We fund and support research into childhood cancers, and we help young patients and their families with our expert, high quality and award-winning information resources.

If you have any comments on this booklet please contact us at the address below

CCLG publications on a variety of topics related to children's cancer are available to order or download free of charge from our website

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