

UNDERSTANDING AND SUPPORTING PATIENTS WITH PARENTAL ROLES



CAROLINE LEEK



FRUITFLY
COLLECTIVE

POLL

- 1) A patient asks, “How do I tell my kids?”
- 2) The prognosis of a patient with young kids changes to palliative
- 3) A patient is refusing to engage with their kids about diagnosis

TRAINING OBJECTIVES



- Understand the impact of parental cancer on patient's children
- Improve confidence in talking to patients about their children
- Explore family support & age-appropriate resources

WHY?



PARENTS

Struggle to know how to support
How best to talk to them
Failure at being a parent

CHILDREN

Higher risk of developing negative psychosocial problems
Heightened by poor communication

NURSES

Limited resources, skills & education
Lack of confidence
Own fears

BEING A PATIENT AND A PARENT



**GOOD
ENOUGH
PARENTING**

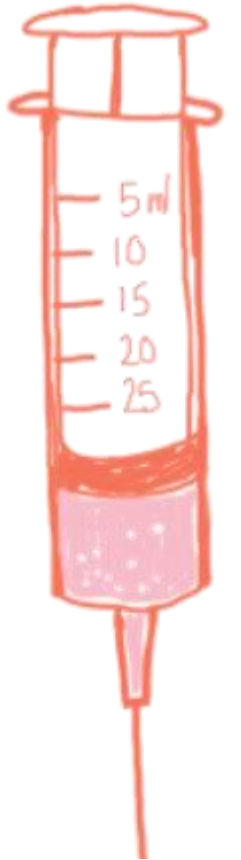
Meeting children's health & developmental needs
Putting children's needs first
Providing routine and consistent care

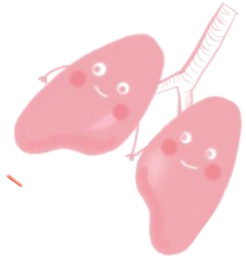
**RISKY
PARENTING**

Neglecting basic needs
Chaos and lack of routine
Putting adults' needs first



- A basic level of understanding about illness
- Believe they have caused the cancer
- Think cancer is contagious





6-11
Yrs



- Understand that people can have serious illnesses
- Understand more about cancer, cells and the body
- Feel responsible for causing the cancer

Teens

- Similar understanding as adults
- Truth not sugar-coated
- May believe that stress has caused the cancer



Curious and interested in learning about cancer

Aware of cancer from the media, campaigns etc

Have the capacity to understand cancer

Don't have the same fears as adults about cancer

Enjoy the opportunity to speak about cancer

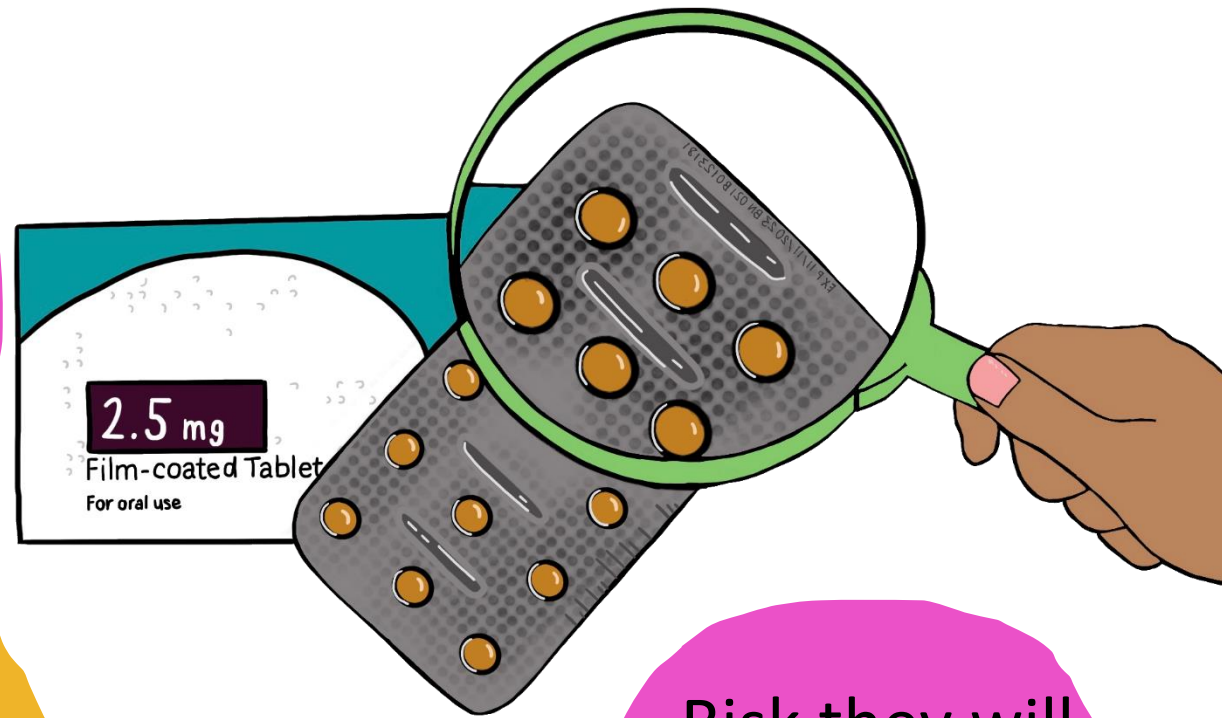


BARRIERS



Protect their child
Denial
Lack of understanding
Want to maintain normality
Feeling overwhelmed
Fearing the child's response
Cultural stigma
Religious beliefs
Fear of losing child

Children easily pick up on things AND have amazing imaginations



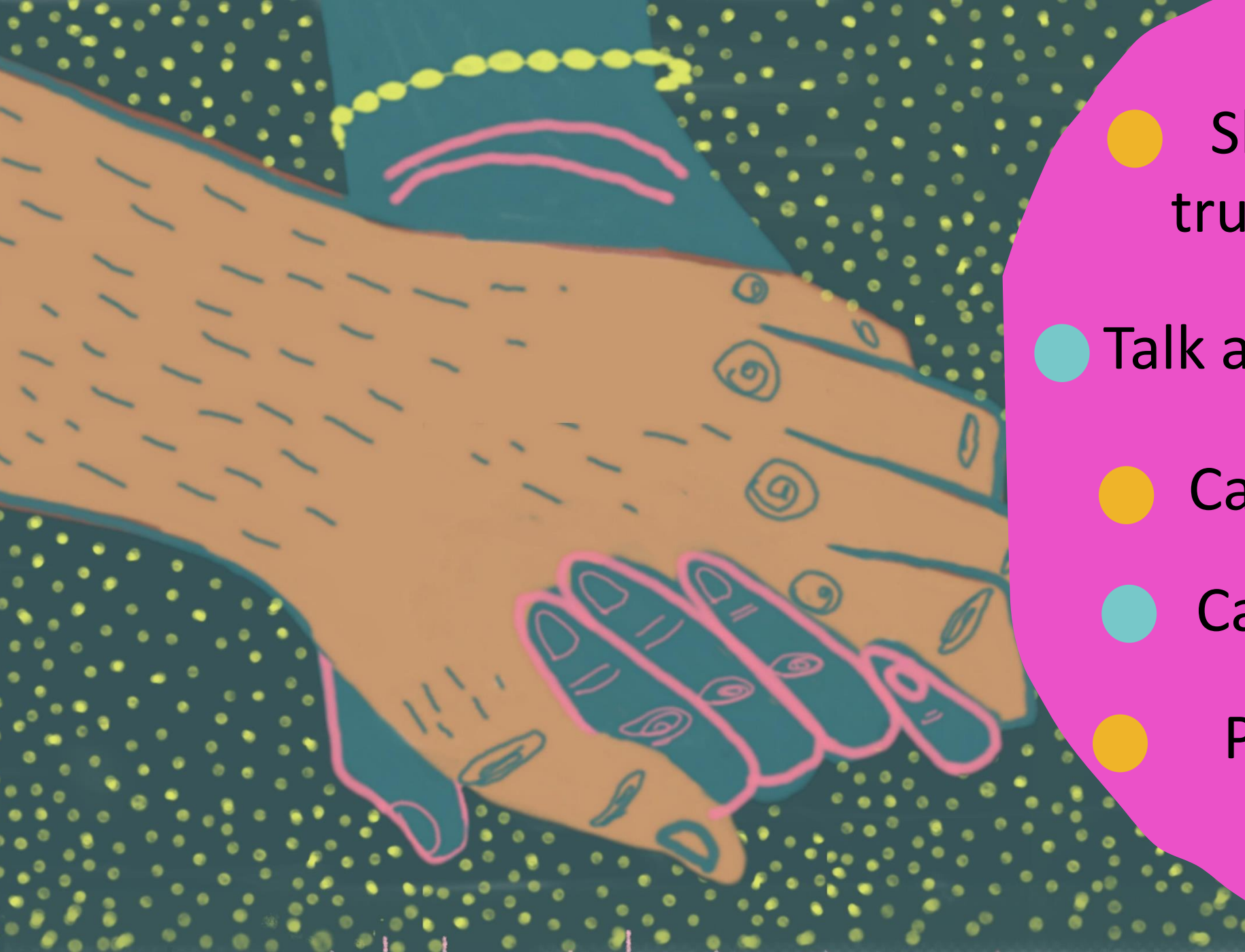
Not telling them, or giving partial or incorrect information is more worrying than the truth

Risk they will find out another way

Feel hurt and left out

Keeping secrets is difficult





- Shows they are trusted and valued
- Talk about their feelings
- Can ask questions
- Can help at home
- Prepare for the future

WHERE TO START?

Tell them as soon as you are ready

Ask someone you and your children trust to be with you

Rehearse what you might say

Calm space and a quiet time of day
- sitting/holding hands

If you have more than one child, try to tell them together

Allow time to process information - silences are OK

Don't assume they have the same fears as you

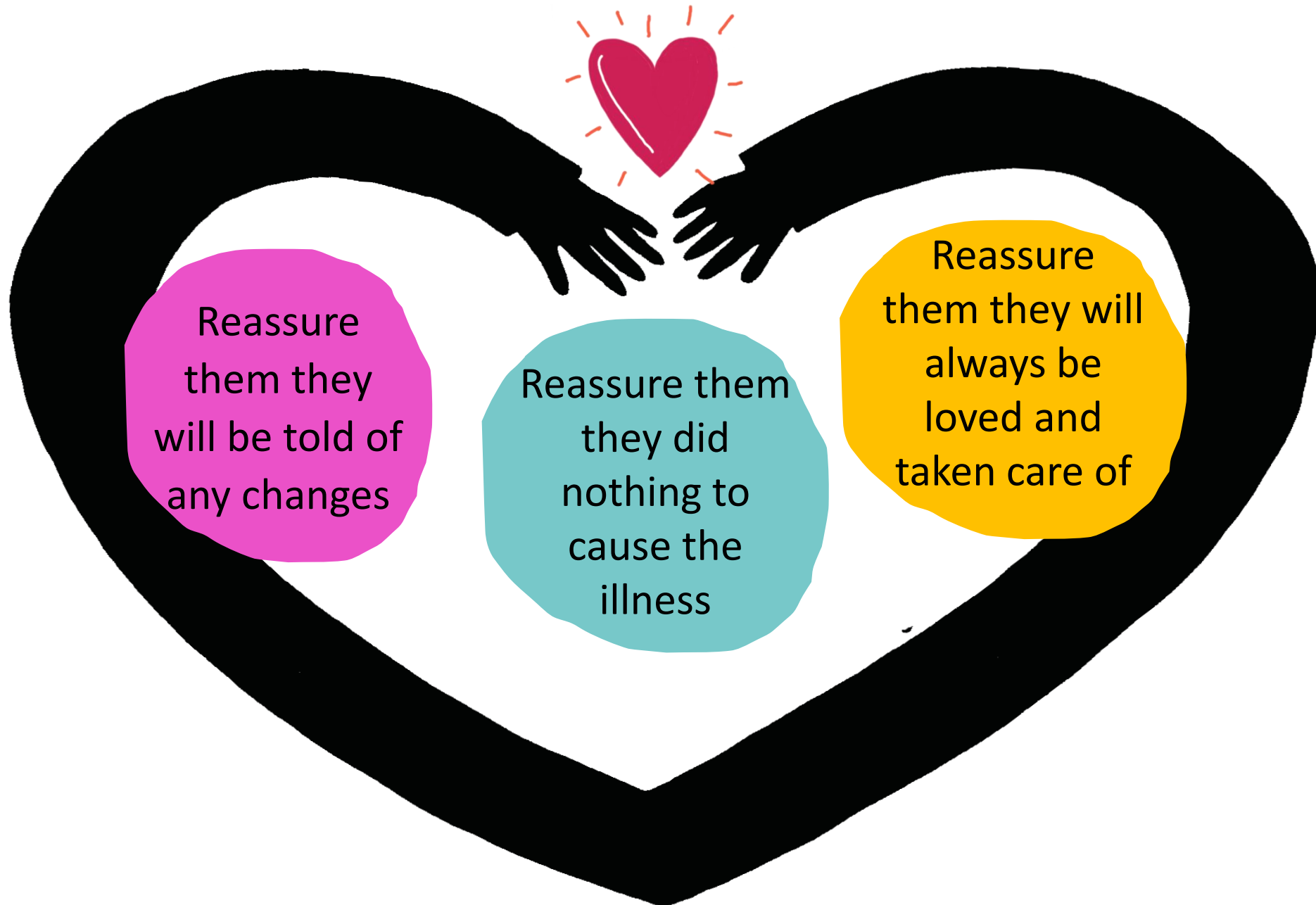
Be honest and don't use misleading ideas

Crying is OK – shows that expressing emotions is normal

Tell them what you currently know. Try not to predict the future

Ask if they can repeat what you have told them

It's OK to not to know answers to all the questions



Reassure them they will be told of any changes

Reassure them they did nothing to cause the illness

Reassure them they will always be loved and taken care of

WHAT TO SAY?

“Mummy/Daddy is sick and needs to take some medicine”

“I have an illness called cancer.
It means some cells are misbehaving in my body.
It means some lumps are growing inside my body that shouldn't be there. The lump is called a tumour.
The doctors will be looking at the best treatments to make me better”

“I have an illness called cancer. The type of cancer is called....
The doctors have designed a treatment plan, which includes....”





IDEAS FOR PROPS TO HAVE WITH YOU



Homemade first aid kits for
their soft toys

Fluffy cancer cells and fluffy organs
by GiantMicrobe

Favourite programmes,
e.g Peppa Pig visit her
friend in hospital

The app ‘Kids Guide To
Cancer’

Books about being ill, cancer,
going into hospital/to the doctors

Activity Books about the body
Books about cancer

Animations on YouTube

Riprap

(www.riprap.org.uk)

Canteen

(www.canteen.org.au)

WAYS TO SUPPORT CHILDREN

Keep routines and schedules consistent and explain any changes to their schedule.



Acknowledge and validate their feelings and worries.

Basic need is feeling secure

Security is being loved, being informed, having boundaries

Create a daily timetable, monthly timetable

Help them identify their feelings, e.g. read stories/watch films about anger, guilt, shame

Create a worry boxes

Discuss safe outlet for strong feelings, e.g. throwing a ball/ripping up paper

WAYS TO SUPPORT CHILDREN

Include them in the family decisions

Age-appropriate information

Time Out & Happy Lists

Give them a way to help

Help around the house

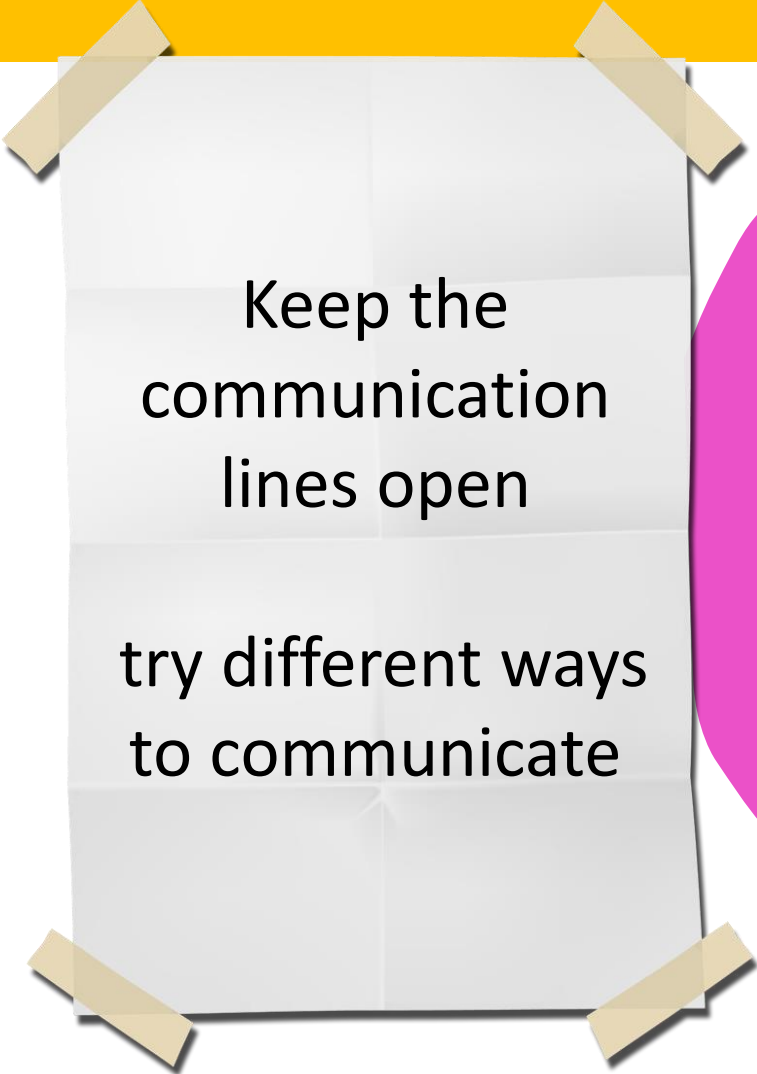
Resources/websites/app

Permission to have fun, be with friends

Plan fundraising events



WAYS TO SUPPORT CHILDREN



Keep the
communication
lines open

try different ways
to communicate

Talking in the car

Whatsapp messaging or
Post it notes

Family meetings around the
table

Going to favourite
café/park
to talk once a week



FACILITATE
CONNECTIONS

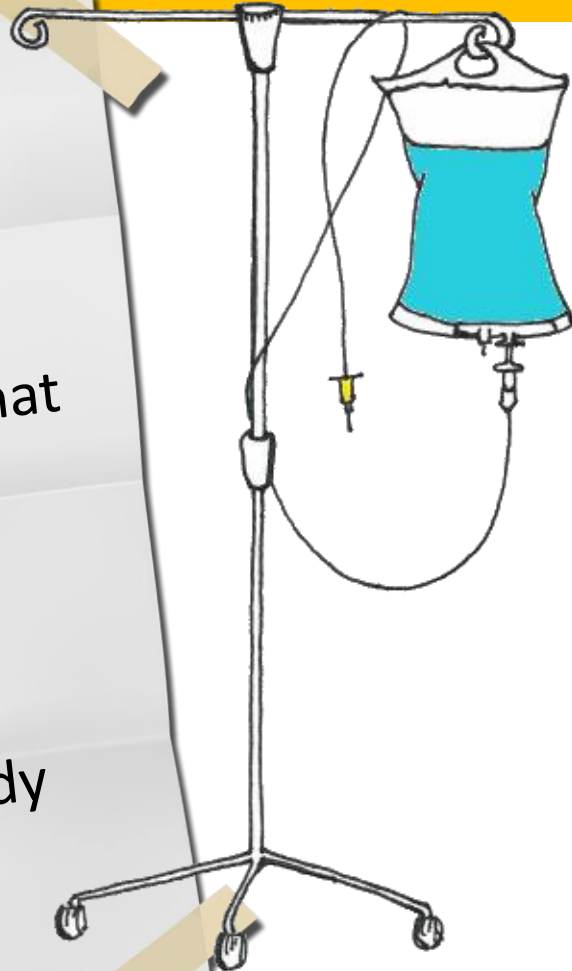
IDEAS FOR INPATIENTS

Video calls, voice notes

Use T-shirts/blankets that smells of their parent

Tie a photo of parent to a teddy

Pocket friends



different types of hugs

Provide fiddle items, kit of resources

Make a safe place for each child to sit

(Remember children might want to be in the room but not sit staring at patient – make space on the floor facing away)

IDEAS FOR OUTPATIENTS

Normalise the event
of having treatment
not an imaginary
scary place

Provide a
connection
between you
and the child

Facilitate parents
telling their
children

Give patients first aid kit for
kids

Give patients a
port/drain/stomabag to take
home to prepare their kids or
Offer to take photos of
equipment, ports, etc

Photoshoot a cuddly toy

Write a note to the child

Resources on site –
book/kits/flashcards/
worryboxes



www.fruitflycollective.com

Cancer Cloud Kits | Toolkits for families



Hedgehog Cloud Kit
3-5 yrs

Tiger Cloud Kit
6-11 yrs

Cancer Cloud Kit
11+ yrs

TOOLS

Educational
Communication
Emotion wellbeing
Coping strategies

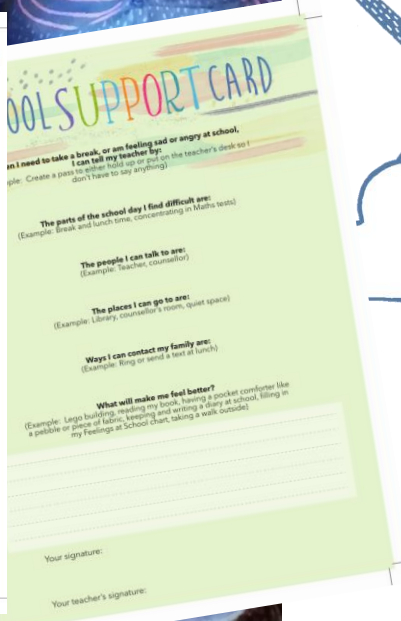


www.fruitflycollective.com

Cancer Cloud Kits | Toolkits for families

Pip's Kit | Toolkit for parent in palliative care

Education
 Communication
 Emotional well-being
 Practical solutions
 Coping skills



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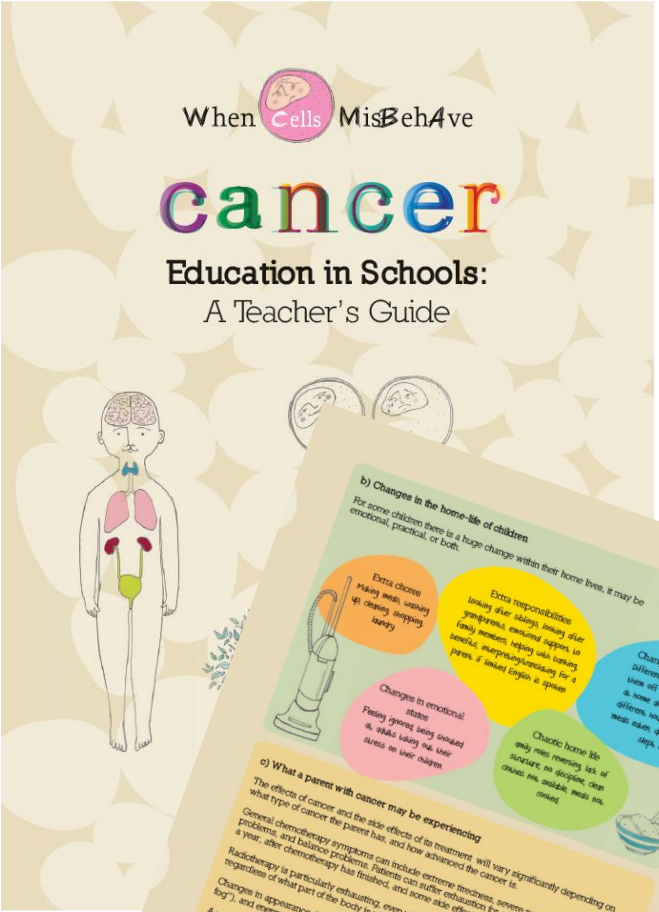
Comics & booklets | For parents, schools & HCPs



Telling your child you have cancer

COMIC STRIPS:

- Panel 1:** I HAVE SOMETHING TO TELL YOU...
- Panel 2:** THEY MAY START TO IMAGINE MUCH WORSE THINGS AND...
THINK THAT THEY ARE TO BLAME.
- Panel 3:** IF YOU DECIDED TO BE OPEN WITH YOUR CHILD AND TELL THEM ABOUT YOUR CANCER DIAGNOSIS...
I AM A SHAKING SUPPORTER TO TELL YOU...
- Panel 4:** THERE WOULD THEN BE NO REASON TO HIDE YOUR STRESS AND WORRIES IN SECRET.
- Panel 5:** YOUR CHILD WILL FEEL INCLUDED, SUPPORTED AND MORE IMPORTANTLY WON'T BLAME THEMSELVES.
- Panel 6:** PROTECTING YOUR CHILD AGAINST HARM CAN BE MORE HARMFUL TO LEAVE THEM OUT.
SO HOW DO YOU TELL THEM?



When Cells MisBehave

cancer

Education in Schools:
A Teacher's Guide

b) Changes in the home-life of children
For some children there is a huge change within their home lives, it may be emotional, practical, or both.

- Extra chores:** Making meals, washing up, cleaning, laundry.
- Extra responsibilities:** Looking after siblings, making after-school arrangements, helping with homework, emergency/transporting for a parent, if a parent organ a spouse.
- Changes in childcare:** Different adults dropping them off at school, being different, having different, less sleep, in.
- Changes in emotional status:** Feeling general being unwell, or, child taking on the stress on their child.
- Chaotic home life:** Family often reorganising, lots of disruption, no discipline, can cause no, outside, inside, no, control.

c) What a parent with cancer may be experiencing
The effects of cancer and the side effects of its treatment will vary significantly depending on what type of cancer the parent has, and how advanced the cancer is.

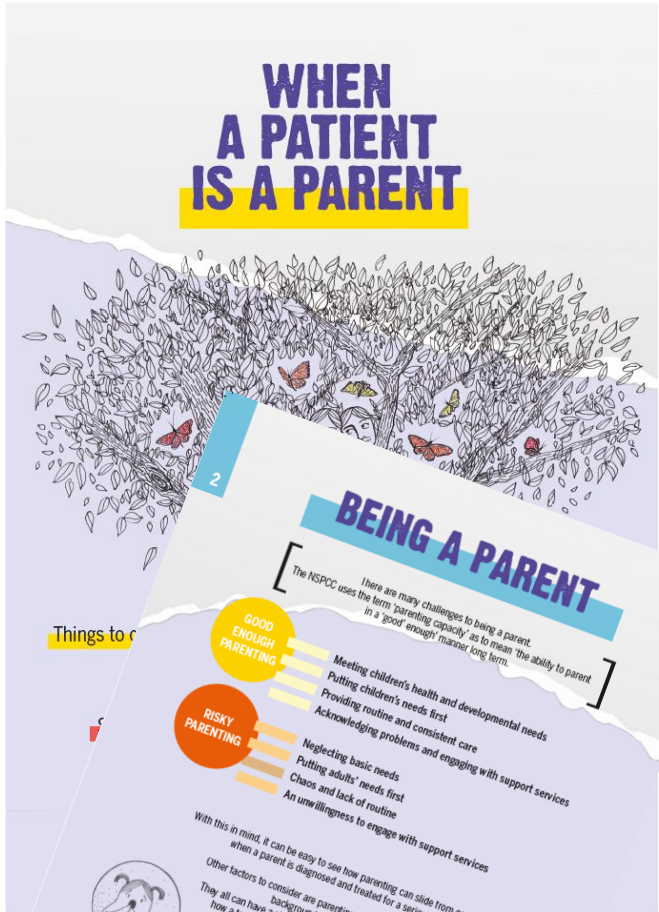
General chemotherapy symptoms can include extreme tiredness, severe nausea, hearing problems, and balance problems. Patients can suffer exhaustion for a long time, sometimes up to a year, after chemotherapy has finished, and some side effects are permanent.

Radiation therapy is particularly exhausting, even without chemotherapy. It can be debilitating regardless of what part of the body is treated.

Changes in appearance (hair loss, weight loss), mobility, memory ("chemo brain" or chemo fog), and energy levels, can affect a parent's ability to care for their child.

A parent with cancer often feels high levels of anxiety, as well as other negative emotions such as sadness, embarrassment, depression, anger, and withdrawal. These feelings combined with feelings of inadequacy about not looking after their child's basic needs can greatly impact their level of coping.

Examples of how treatment of different cancer types can affect family life: Breast cancer can mean missing baby and toilet difficulties. Ovarian cancer can mean not being able to eat, or being fat through a tube. Head and neck cancer can cause severe difficulties.



WHEN A PATIENT IS A PARENT

BEING A PARENT

There are many challenges to being a parent. The NSPCC uses the term 'parenting capacity' as to mean 'the ability to parent in a 'good enough' manner long term.'

- GOOD ENOUGH PARENTING**
 - Meeting children's health and developmental needs
 - Putting children's needs first
 - Providing routine and consistent care
 - Acknowledging problems and engaging with support services
- RISKY PARENTING**
 - Neglecting basic needs
 - Putting adults' needs first
 - Chaos and lack of routine
 - An unwillingness to engage with support services

With this in mind, it can be easy to see how parenting can slide from good to risky when a parent is diagnosed and treated for a serious illness.

Other factors to consider are parenting styles, and different cultures, backgrounds and family beliefs. They all can have a significant impact on how a child is brought up, how a family communicates, and how 'illness' is perceived.

AT ONE END OF THE PARENTING SCALE IS 'CONTROLLING', WITH RIGID BOUNDARIES, AND THE OTHER END, 'CASUAL' WITH NO BOUNDARIES. SOME CULTURES VIEW CANCER AS SOMETHING TO BE SHAMEFUL ABOUT.

www.fruitflycollective.com

Cancer Cloud Kits | Toolkits for families

Pip's Kit | Toolkit for parent in palliative care

Comics & booklets | For parents, schools & HCPs

Museum Inside Me | Books



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Other resources

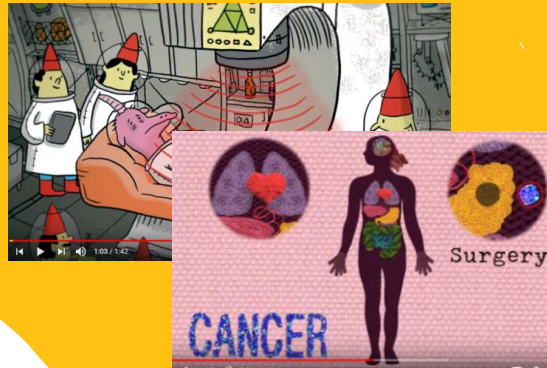
FREE APPS

camp  quality.

KIDS' GUIDE TO CANCER



ANIMATIONS



DOWNLOADS



BOOKS



FLASH CARDS LITTLE C CLUB

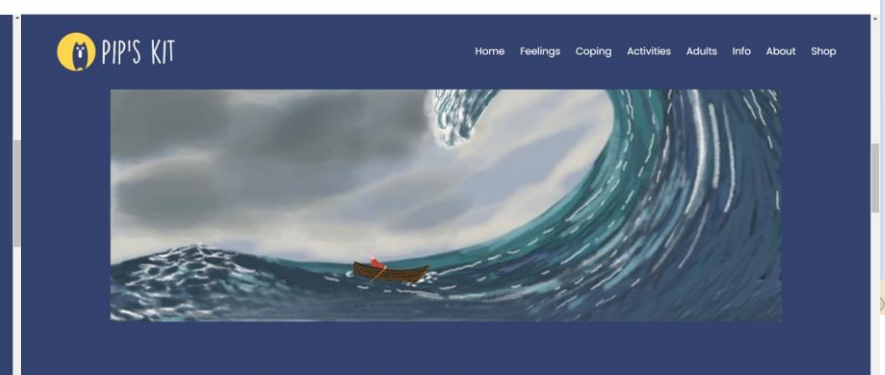
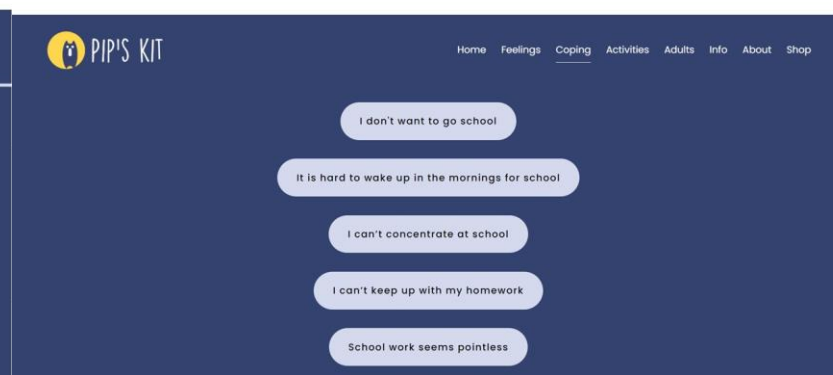
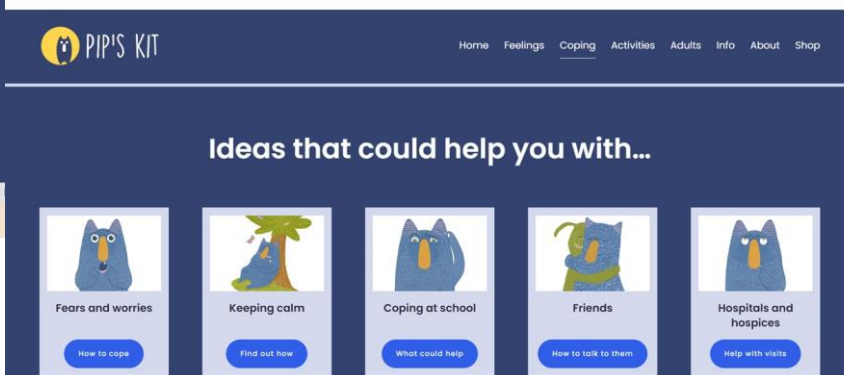
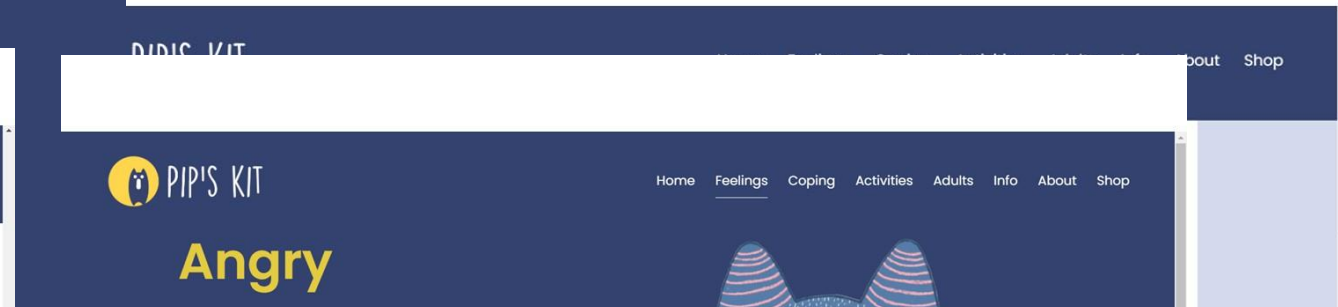
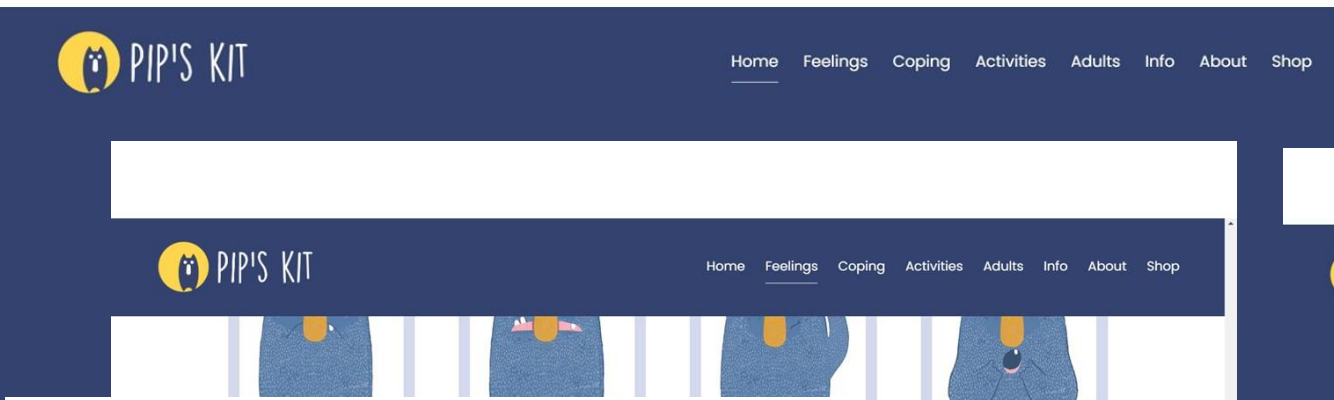
SIGNPOSTING

<http://www.riprap.org.uk/>



www.pipskit.co

Free online version 5-10 yr with parent in palliative care



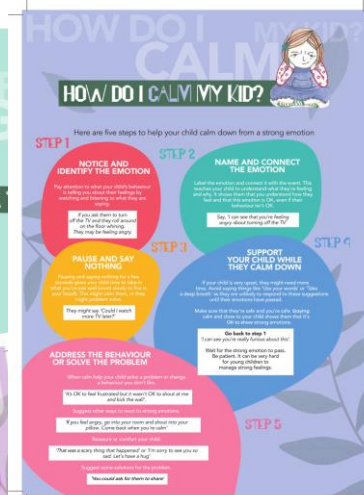
www.parentingwithcancer.org

Coaching | Workshops | Resources | Support network



3AM WORRIES

BROWSE OUR PARENT TOOLBOX



CALMING MY KID

go



HELP WITH SCHOOLS

go



FEELINGS & EMOTIONS

go



TALKING TO KIDS

go



NEW BEHAVIOURS

go



PARENTING FROM BED

go



Parenting with Cancer conference

Sat May 25th London

Tickets via www.parentingwithcancer.org



FRUITFLY COLLECTIVE

www.fruitflycollective.com

www.pipskit.com

www.parentingwithcancer.org

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