

NURTURE

W E L L B E I N G
M A G A Z I N E

FOR PARENTS & CARERS OF CHILDREN WITH CANCER

*coping strategies /self-care/ finding
purpose/connecting through shared experience*



WRITTEN BY PARENTS. FOR PARENTS

DEAR PARENTS & CARERS...

My name is Kate and I'm mum of Amber, diagnosed with rare cancer Synovial Sarcoma aged 8 in 2018. It's been a long journey, but Amber is currently fit and well.

During my time as a parent of a child with cancer, I came to realise how important it was to take care of my own wellbeing, so I could look after my little girl in the best way possible while she faced treatment. To begin with, this was an extremely difficult task – I felt completely shocked, traumatised and overwhelmed, hardly able to function let alone look after myself and my family...



Kate & Amber



Resilience in the face of adversity

...But as time passed and through trial and error, I discovered a range of tools and strategies that I found useful. This magazine edition includes some of those very tools, to support you in building resilience and coping skills, with information on how to protect your emotional and mental health as best you can, during such difficult times. Hints, tips and useful information shared by other parents are also featured. If you would like to subscribe to further magazine editions, please contact info@cmk-cic.org.uk.

To any parent who has heard the most devastating truth imaginable – that their innocent, beautiful child has cancer; I see you, I feel you, I have been you and, often, I still am you. I say this for you as much as for me: you must believe that, one day, things will somehow feel okay again x

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THE IMPORTANCE OF PARENT WELLBEING IN CHILDHOOD CANCER



If you're reading this magazine, it's possible that you've recently discovered your child has cancer, and that looking after your own wellbeing is the last thing on your mind right now. However, it's important that, where possible, you set aside time to take care of **you** as this, in itself, can help in supporting your child.

Research has shown a relationship exists between parent and child distress in childhood cancer - meaning that, the more stressed, fearful and anxious

you are, the more stressed, fearful and anxious your child may become.

Remaining calm and hopeful in this experience is easier said than done, however, and can feel impossible. Continue reading to discover a number of coping strategies that might support you in lowering your anxiety levels and building emotional resilience through practices of self-care, so that you can be there to support your child in the best way possible...

What are coping strategies?

A conscious effort to manage stress and reduce negative emotions with techniques & problem solving.

COPING STRATEGIES

THE ART OF DISTRACTION

You're in the shower, washing up or lying in bed unable to sleep - your mind, racing. These thoughts are fuelled with worry for your child's future - they're distressing, may feel uncontrollable and spiral as you constantly search for solutions that feel out of reach. Intrusive or unwanted thoughts are a shared experience for many parents of children with cancer. They're both distressing and unhelpful. If your thoughts become too difficult to bear, it's important to reach out to your GP, but there are also strategies you can put in place for yourself.

Notice if there is a pattern to these thoughts and the times they most crop up. For me, this would be every time I showered, or when waiting for Amber to come out of surgery. Work out distraction techniques and resources that will benefit you in these moments. For example, listening to podcasts (like Fearne Cotton's 'Happy Place') are a great means of distraction for me. I always have a pair of headphones in my bag so I can pop on a podcast, distract my thoughts and learn something new. I often listen to other people's experiences of hardship and the tools they used to overcome challenging times, as feel this is helpful to me.

Books and rubbish TV are also great escapes - they allow me to escape to another world, and gain space away from the difficult circumstances we are facing.



"I like to try and go for a run or walk in the woods with the dogs, or listen to podcasts that are completely unrelated. BBC Sounds have some good ones."

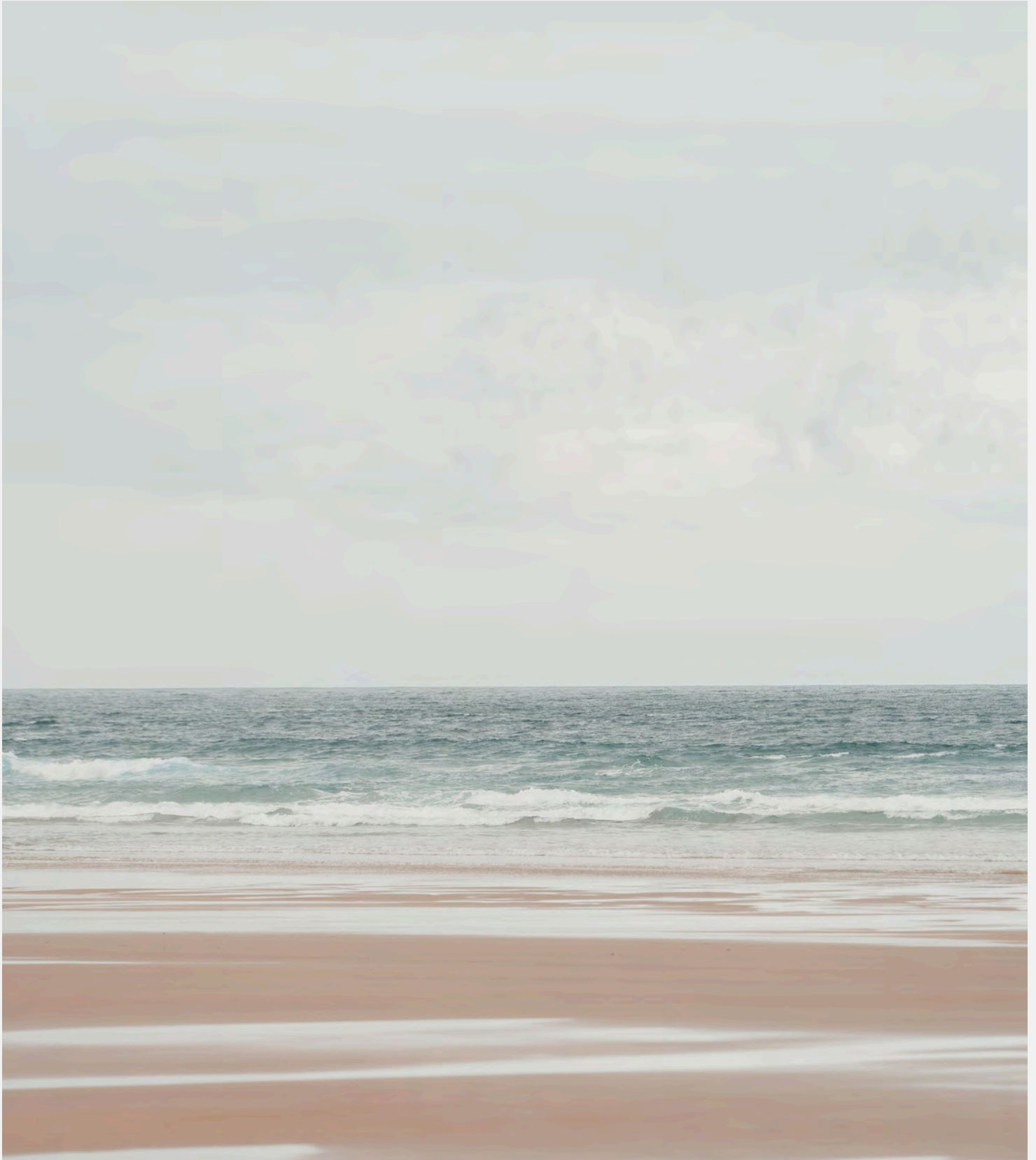
Lucy Stead, mum of Immy

"For me, Headspace, gardening and swimming. I also used Maggie's a lot when Lewis was having chemo. I helped in the garden and chatted with other carers."

Diane Seed, mum of Lewis

"This too shall pass".

If you're experiencing uncontrollable thoughts, remember that all thoughts are temporary and will eventually pass. A thought is just a thought, not a truth or premonition...



If you're able to find time, include walks in nature as part of your self-care routine. Spending time in nature while tuning in to the sounds, smells and details of the natural environment is proven to positively impact mental wellbeing, whilst decreasing stress and anxiety levels.



FINDING PURPOSE

“Finding a sense of accomplishment and purpose in the days following my daughter’s diagnosis meant I felt some control in a situation that felt otherwise unmanageable.”

Our wellbeing is influenced by the sense of control we feel in our lives and over our destiny. At the point in which, as parents or caregivers, we’re told our child has cancer, we’re unexpectedly thrown into a world in which we feel an extreme lack of control, not knowing what to do or what to expect and fearful over what lies ahead. We’re used to making everything okay for our children, and suddenly we feel disempowered and unable to do so, feeling as if we have no influence over the course of events.

Try to consider where you might be able to achieve a sense of purpose and control in your every day. This might be educating yourself around treatment options available to your child, or simply through the accomplishment of a daily activity which might support your family whilst giving you a sense of purpose. For me, choosing a recipe for a healthy, immune-boosting dinner each day, fetching the ingredients and preparing the meal from scratch for my family created a sense of daily purpose, and improved my mindset and wellbeing. I also decided to decorate my daughter’s bedroom, so she was comfortable and happy at home.

“Finding and preparing an immunity-boosting dinner from scratch for my family each day, gave me a real sense of accomplishment & purpose.”



STRENGTH IN UNITY



Research has shown that an effective way of protecting parent wellbeing in childhood cancer is through support networks you have in place with others. However, many are actually less likely to seek out this kind of support due to time spent caring for their child.

Often parents feel alone and isolated and can feel as if nobody else can relate to what they're going through. That said, it's important to lean into the support, love and care of close family or friends, to help in protecting your emotional resilience.

Tip:

Write a list for family/friends to let them know how they are able to help. E.g. the weekly shop or a walk together in nature.

Another way to build strength in unity is in connecting with others who share lived experience. Initially, this was difficult for me as I was terrified that any hope I had for my daughter would be destroyed if I heard of another child in Amber's position with a less positive prognosis. As time has progressed, however, I've come to understand that every single case of childhood cancer is different, even for two children with the same sub-type.

I've since become involved in two parent support groups, one nationwide for Sarcoma UK and another local group for parents in East Kent. Groups such as these can be a great source of emotional and practical support and information.

Social Support...

You are not alone



Join our peer support group, for parents/carers of children/teenagers/young adults with a cancer diagnosis, wherever you are in your family's journey.

This group is run by a parent of a child with a cancer diagnosis in Kent, for parents/carers with shared experience.

It is an opportunity to come together, feel supported locally and build hope pathways, shared resilience and coping skills after your child's diagnosis. There will also be opportunity to engage in some free wellbeing activities.

Register now.



info@cmk-cic.org



CMK



MONTHLY MEET UPS ONLINE & IN PERSON

Send us an email for further information on dates and locations near you.



FOR PARENTS, FROM PARENTS

We spoke with a national peer support group for parents and carers of children with cancer, to find out what parents do to take care of themselves whilst looking after their children in the best way possible. Here's what they said...



To look after my wellbeing I “try to go for a run or walk in the woods with the dogs - I listen to podcasts that are completely unrelated, BBC sounds always have good ones. I’ve also used Headspace which is very good”.

Lucy, mum of Immy

“I go for a run, bake flapjacks, clean, watch comfort TV, make a cup of tea, or go to an exercise class. My therapist and I made a list of five, twenty and sixty minute activities for stressful moments, which has really helped. Oh, and forests - trees! Nature helps.”

Jennifer, mum of Eva

“I plan something for us to look forward to - a mini trip, a meal out, a photo studio for Liz to take photos in - small positives that help the tricky days feel better”.

Vicky, mum of Liz

“MY THERAPIST AND I MADE A LIST OF FIVE, TWENTY AND SIXTY MINUTE ACTIVITIES FOR STRESSFUL MOMENTS, WHICH HAS REALLY HELPED”.

“For me, Headspace, gardening and swimming. I also used Maggie’s a lot when Lewis was having chemo. I helped in the garden and sat and chatted with other carers.”

Diane, mum of Lewis

“One thing Immy and I are enjoying doing together when in hospital are puzzles. We aren’t hardcore puzzlers, but someone told me about these little sorting trays that you can get that are very handy for hospital...It’s a good talking point for staff too.”

Lucy, mum of Immy

“ORGANISING THINGS TO MAKE MY DAUGHTER SMILE, ALSO MADE ME FEEL BETTER.”

“I’ve been wondering how I’ve coped and the short answer is we were with Francesca all the time so rarely let our guards down. We were in [hospital] all the time she was so couldn’t do anything normal. We used Maggie’s though and talked to people there who were so supportive”.

Sharon, mum of Francesca

Organising things to make my daughter smile (like a card from her classmates, or a teddy bear) also made me feel slightly better, as did making sure I felt comfortable during hospital stays, with a new pair of slippers or PJs.

Kate, mum of Amber

TO GOOGLE, OR NOT TO GOOGLE?



THAT IS THE QUESTION..

Vicky and Jennifer - parents from Sarcoma UK's parent peer support group - offer the following advice on Googling information on your child's cancer...

Vicky: "I'm conscious this could have the opposite effect for some people but if I'm worried, I Google. I usually find concrete facts help me to feel calmer. They also help me to decide if my worry is rational or irrational and to try to define what I'm worried about which makes it feel less overwhelming than worrying about everything".

Jennifer: "Consider your Googling habits/needs as most people decide themselves if it's helpful or not. Mostly I heard 'don't Google' which was good for me but, if I was like Vicky, that might have been hard to hear and perhaps limiting and unhelpful. If parents know themselves and feel facts will help them, using the internet could be a relief. But I would say for parents to direct themselves to good sources like Macmillan or Sarcoma UK".

I WISH I'D KNOWN...

TIPS FOR PARENTS WHOSE CHILDREN HAVE JUST BEEN DIAGNOSED

We recently caught up with Anna, mum of Sam who was diagnosed with osteosarcoma in 2017 aged 10. We asked Anna what tips she'd offer parents/carers of newly diagnosed children and she kindly shared the following:

**“THERE IS NO
RIGHT WAY TO
NAVIGATE
THIS”**



“There's no right way to navigate this - you need to decide as a family how to get through it. We decided not to tell people much until we knew what the situation was at all points, we didn't want to manage other people's emotions. We also decided to both keep working which others found hard to understand but we found it kept us sane.”



“REMEMBER THAT THERE ARE PEOPLE LIVING WITH CANCER, IT DOESN'T NECESSARILY TAKE OVER YOUR WHOLE LIFE”

Check in with family through mass communication like social media and group chats or by getting groups to update other groups e.g. grandparents update aunts and uncles - We found that lots of people assumed that either things were awful or everything was OK because they hadn't heard anything and didn't want to ask. This then either created awkward discussions when we saw people or meant people were upset or stressed unnecessarily.

“Remember that there are people living with cancer, it doesn't necessarily take over your whole life - we've been living with cancer in our family for seven years and many days just look like everyone else's with holidays, meals out, giggles at the dinner table, normal teenage and family arguments and just every day life things. We found this difficult to navigate as we had thought cancer would be all encompassing, we hadn't thought about how we'd live day-to-day life around it.”

“CHECK IN WITH FAMILY THROUGH MASS COMMUNICATION LIKE SOCIAL MEDIA”



“LOOK AFTER YOURSELF”

This doesn't have to be big things it can just mean having a nice shower gel and lip balm in your hospital bag and having a shower each day.



“JOIN SUPPORT GROUPS EARLY”

Join support groups early. We didn't want to be in groups as we were scared of what we'd find out and only wanted to talk to oncologists and the medical team, but I wish we'd joined groups earlier just to make sure that we had another source of support and advice.

“IGNORE OPERATION TIME ESTIMATES”

In our experience these have always been inaccurate and just create more stress! Either they're much shorter and then you can't be found when your child goes into recovery, or they're much longer and you then can't find out what's going on!

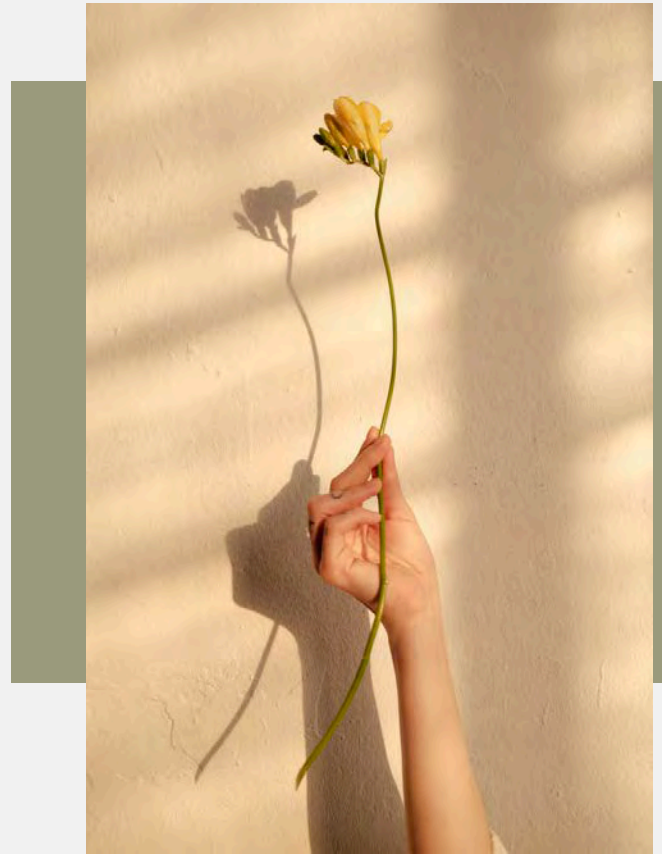
Advice from Anna Harvard.

HOPE

& WHY IT'S IMPORTANT

By Kate Munday-Hector

Hope is the belief that things will improve in the future – that the current situation will shift and better things will come. Scientific research has shown that, regardless of the challenges faced in experiences of childhood cancer, parents and caregivers are able to maintain hope, even in situations where their child has a poor prognosis...



Hope & PARENT WELLBEING



...This is important because evidence shows that maintaining hope can protect our wellbeing, reduce our risk of anxiety and depression and support us in actively meeting the demands and challenges which come with caring for a child with cancer. The inner strength of hope has been shown to enhance parents' resilience, overcome their inner fears and remain active in coping with their child's illness, staying on track with treatment and trying new options where needed.

So how, as parents and caregivers, do we create and maintain hope during the course of our child's cancer journey?



Inevitably, the level of hope we experience will shift and fluctuate at different points in our child's illness, and we may encounter barriers to hope, such as a deterioration in our child's health, anxiety over cancer returning or the impact of our child's cancer treatment and the emotional and physical toll we face as parents. There are, however, ways of keeping that hope topped up and active.

Recent studies have evidenced that parents of children with cancer have benefitted from these sources of hope during their child's illness. Tapping into these can support you in building and maintaining your own hope pathways, as will paying attention to those moments which elicit hope for you personally; for instance, learning of another child's story of survival, or seeing a family continue to thrive regardless of their child's prognosis. →

AS EXPLORED BY CHUN-YAN LIU ET AL. IN THEIR ARTICLE 'HOPE EXPERIENCES IN PARENTS OF CHILDREN WITH CANCER' . EUROPEAN JOURNAL OF ONCOLOGY NURSING. 70 (2024). 1-12.

- 1** The **strength, perseverance** and **resilience** their child shows, and drawing from his/her **positive behaviour and approach**.
- 2** The **constant help, expertise** and **compassion** of **medical staff**.
- 3** **Social support** from family, friends, colleagues and extended networks, creating a **sense of unity in the fight against cancer**.
- 4** **Having faith**, whether in religion, your child's oncologist, in yourself or even in continued hope.

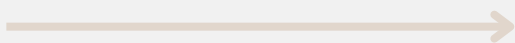
Positive psychologist Charles Snyder's Hope Theory argued that three key things make up hopeful thinking:

- 1 Goal** - thinking with clear goals in mind
- 2 Pathways** - finding different routes to achieve your goals (whilst acknowledging any obstacles)
- 3 Agency** - a belief that you can continue in progressing and moving towards your goals and have the ability to change course where needed.



See 'Snyder's Hope Theory', accessible online at mindtools.com

An example of how Snyder's theory might relate to our current situation as parents of children with cancer is the following:



- 1 Goal** - to improve my child's wellbeing
- 2 Pathways** - psychological support with a therapist/accessing free wellbeing support from a charity/connecting my child with others of similar experience/supporting my child in practices of self-care.
- 3 Agency** - I believe that I can identify how to enhance my child's wellbeing and find/use a variety of resources available to support me in doing so.

Use this space to jot down a goal personal to you and your child's journey, its potential pathways and the belief you have in your own ability to progress towards its achievement.

Remember, you can build and maintain hope in ways beyond a cure for your child's illness. In doing so, you can remain resilient and active as a parent whilst caring for your family.

My hope goal:

My hope pathways:

How I will personally ensure we progress towards this goal:

Meet Arabella – children's oncology nurse turned personal-stylist and colour analyst. Arabella is enthusiastic about the use of colour to support and enhance wellbeing, and has written the following feature to support parents and carers in using colour for parent/child wellbeing in the experience of childhood cancer.



ARABELLA DUFFILL

hello@arabellapersonalstylist.com



I know this must be such a difficult time for you. From the bottom of my heart I'm sending you lots of love and positive colourful vibes x

THE PHENOMENON OF COLOUR

How does colour support wellbeing in paediatric cancer?

Colour is a phenomenon. It surrounds us all of the time and yet we are only conscious of a few of the colour decisions we make; for example, choosing the strength of your cup of tea or checking if food in the fridge has turned brown and is out of date.

Colour is light and light is energy. We encounter it through our eyes where it hits receptors and initiates electrical messages to our brain. Our brain subconsciously reacts to external inputs all of the time. Light/colour makes up a big part of that stimuli and evokes physical responses in our bodies that can impact emotion, body temperature, metabolism, sleep, the nervous system, our appetite and more. Colour is so powerful it can affect our wellbeing and, by understanding it, we can use it as a tool in challenging times. Here are a few examples:

Green can be a reassuring and calming influence. It is restful for your eyes and indicative of balance and harmony. Green makes us think of nature & new life growing which is why it can be relaxing to have plants in your line of vision - be it in a bedroom, living room, near a desk or even in your child's hospital room.

Blue is also calming and promotes clarity of thought. It's a good colour to have in bedrooms or to wear when caring for your child and looking to create calmness. It can help to evoke the release of oxytocin - the love/cuddle hormone which makes you feel warm and fuzzy. Both blue and green are good colours for rooms, bedlinen, backgrounds, clothes or pyjamas.

Red and **yellow** stimulate the part of the brain which dilates blood vessels and increases blood flow, heart rate and blood pressure.

Red is especially great to wear when you need a boost of energy, confidence or to feel strong. There may be tricky days when you need to feel like you've got this, you can do this - red can help you feel more empowered.

Yellow encourages a sense of optimism and joy, but a whole room of it can create irritability. Having a small amount on your body or nearby can help you and your child feel a little more cheerful.

Feelings of warmth, care and compassion are associated with **pink**. Wearing pink may allow you to seem more approachable, loving and open as a parent. Brighter pinks have more red in them, so feel more dynamic and energetic - helpful to wear on those trickier days when you need a bit more oomph.

Orange is uplifting, energetic and playful. Small amounts of orange worn or seen in the daytime, can boost your mood and help you or your child feel more positive.

Black absorbs light, so it doesn't give energy back in the same way as other colours, it can feel a bit aloof, so is best worn in small amounts; whereas white can feel serene but, in large amounts, sterile or clinical. Try to break up large white spaces with some warmer colours.

So that's a whistle-stop tour of the power of colour and its use in supporting our wellbeing. I hope you find it useful and I encourage you to experiment with how you surround yourself and your family with it whilst caring for your child, whether at home or in hospital/clinical settings (I personally LOVE oranges and pinks!).

IN KENT...

CMK (Changing Minds Kent CIC) offer a parent & carer support group specifically for families affected by childhood cancer, and a 'Chums, Chats & Socials' group for young people with cancer aged 16-24. Both groups are led by individuals with lived experience. Email info@cmk-cic.org for more information.

Demelza Kent also offer a broad range of emotional and practical support services for children and families. Visit www.demelza.org.uk/about/demelza-kent to find out more.



HOSPITAL-BASED...

Your child will likely be referred to a specialist cancer hospital after their diagnosis. A variety of charities offer support for children and families in hospital settings, including Young Lives vs. Cancer and Teenage Cancer Trust who provide specialist support in and out of hospital, free accommodation for families to stay near hospitals during treatment and day-to-day care and advice. Charities like Spread a Smile organise activities to bring joy to seriously unwell children and their families whilst in hospital. See www.spreadasmile.org, www.younglivesvscancer.org.uk and www.teenagecancertrust.org.

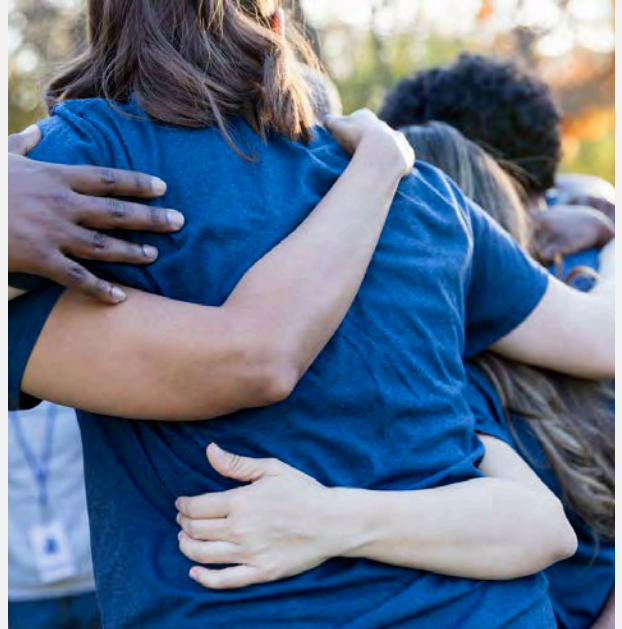
Charities understand what you're going through and how you must be feeling - reach out and include them in your support network, if you're able.

CHARITIES OFFERING SUPPORT

DEDICATED CANCER CHARITIES

A number of national charities have been set up, dedicated to funding research and providing information and advice for anyone affected by specific cancer types. These charities offer telephone support lines, resources, support groups, accommodation and emotional, financial and practical support for parents and families. For example, Sarcoma UK have a support line, information and advice on sarcoma, and a dedicated online parent support group for families of children with sarcoma; Solving Kids Cancer offers support for those affected by neuroblastoma, including access to treatments and clinical trials if they are not available on the NHS and Leukaemia Care is dedicated to providing information and support for those affected by leukaemia.

Cancer charities like these are a great way of finding out information about your child's cancer type and treatment. Your child's Clinical Nurse Specialist may be able to signpost you to further information, or visit www.childrenwithcancer.org.uk for a list of cancer organisations able to help.



FINANCIAL SUPPORT

Charities understand the financial burden experienced by families affected by childhood cancer. Several offer grants to support with this including Young Lives vs Cancer, Children with Cancer UK, Family Fund, Cost of Cancer and the Lennox Children's Cancer Fund. The Bradley Lowery Foundation has been set up to support families launch campaigns to raise funds for medical treatment/equipment not available on the NHS and to support in coordinating travel for treatment abroad.



Often charities offering support for families affected by childhood cancer have been set up by a relative, friend or family member with similar experience.

They are a powerful means of support.

CHARITIES OFFERING SUPPORT

WELLBEING SUPPORT

A number of children's cancer charities offer wellbeing support for families affected by childhood cancer, like the Kids Cancer Charity which provides counselling and family support, as well as holidays and staycations. If you'd like to find a qualified counsellor or psychotherapist able to support in your local area, take a look at the [Counselling Directory: www.counselling-directory.org.uk](http://www.counselling-directory.org.uk). CMK (Changing Minds Kent) may also be able to assist with their peer support groups. Contact info@cmk-cic.org for further information.



SOMETHING TO LOOK FORWARD TO...

Having something to look forward to as a family and for your child is important and helps with maintaining a more positive outlook. Several charitable organisations work to make this possible, funding days out, short-breaks, social gatherings and events, as well as granting wishes for your child. Starlight Children's Foundation organises events for children with serious illnesses like film screenings and boat parties, Make a Wish Foundation grants wishes for children with life-threatening illnesses and Willow Foundation organises special days out for seriously ill adults aged 16 to 40.



SUPPORT DIRECTORY

DEMELZA KENT

Local support services for parents and families of children experiencing serious or life-limiting conditions.

www.demelza.org.uk/about/demelza-kent/

NHS TALKING THERAPIES

Access a free local counselling service via the NHS:

www.nhs.uk/mental-health/talking-therapies-medicine-treatments/talking-therapies-and-counselling/

CHANGING MINDS KENT

Peer support group for parents/caregivers of children with a cancer diagnosis in Kent.

www.cmk-cic.org

MACMILLAN

Macmillan offer a searchable online support directory of cancer services near you. visit:

www.macmillan.org.uk/in-your-area/

CHILDREN WITH CANCER UK

A national charity offering a variety of support, including a useful list of organisations providing help for families. Visit their webpage:

www.childrenwithcancer.org.uk

IT'S NEVER YOU

A national charity offering support, advice and guidance for parents of children with cancer, including an app signposting to financial, emotional and practical support.

www.itsneveryou.com/

YOUNG LIVES VS CANCER

Financial, social & emotional support for young people affected by cancer and their families.

www.younglivesvscancer.org.uk

TEENAGE CANCER TRUST

Help, support and events designed for teenagers and young people diagnosed with cancer.

www.teenagecancertrust.org

N.B. This list is not exhaustive - please speak to your child's Clinical Nurse Specialist for more info.



SPECIALIST CANCER CHARITIES

THE BRAIN TUMOUR CHARITY

Support and information for anyone diagnosed with a brain tumour. Funds research into child and adult brain tumours.

www.thebraintumourcharity.org

NEUROBLASTOMA UK

Neuroblastoma specific information and support for children and families.

www.neuroblastoma.org.uk

BLOOD CANCER UK

Research, support & information on blood cancers, including leukaemia, lymphoma & myeloma.

www.bloodcancer.org.uk

LEUKAEMIA CARE

Leukaemia and blood cancer specific support, advice and information.

www.leukaemiacare.org.uk

SARCOMA UK

Sarcoma-specific information, support and research, including an online support group for parents of children, teens and young people with a sarcoma diagnosis.

www.sarcoma.org.uk

ALICE'S ARC

A children's cancer charity offering research, information and support for children and families affected by rhabdomyosarcoma.

www.alicesarc.org

CHILDHOOD EYE CANCER TRUST

Supporting families affected by retinoblastoma, a rare form of eye cancer.

www.chect.org.uk

GRACE KELLY CHILDHOOD CANCER TRUST

Fund research into rare and aggressive childhood cancers and provide information booklets on specific cancer types and their treatments.

www.gkcct.org

N.B. This list is not exhaustive



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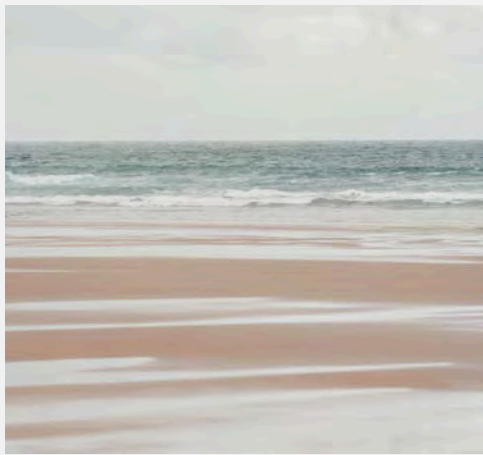
A handwritten signature in a dark brown, cursive script that reads "Kate Munday-Hector".

EDITOR

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M A G A Z I N E

for
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Nº1.

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