

A sunset over a beach with mountains in the background and a path of footprints leading away.

Step by Step

A Parent's Guide to Caring
for a Child with Cancer

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Dedication

This book is dedicated to our donor, a woman in Germany to whom I give thanks and gratitude each morning. Thank you to The Anthony Nolan Trust for finding her and making the bone marrow donation a possibility.

This book is also dedicated to our warrior son, who fought his long battle with such quiet nobility and never once complained going through the gruesome protocols and punishing treatments whilst still a child.

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Your body's
ability to heal is greater
than anyone has permitted
you to believe.



Foreword: Holding onto Hope

“The journey of a thousand miles begins with a single step.” — Lao Tzu

For seven years I have avoided, procrastinated, or possibly have just not been able to write about my youngest son, Ramsey. His diagnosis was Acute Lymphatic Leukaemia, Philadelphia Positive - shortened to ALL Ph+. His story belongs to him, and is not for me to tell. What I was asked to do is recount what I believe could be of help to any other mother, parent or carer who finds themselves holding the hand of someone they love as they go through a cancer diagnosis and a

treatment protocol.

It will be biased towards childhood cancer and in particular this rare and aggressive form of leukaemia, but there will be common situations that any carer may face in a cancer hospital that I believe will be of help.

Holding the hand of your child and making countless critical decisions on their behalf day in and day out. Decisions that will affect survival outcomes of not only your child, but yourself, your marriage, your family who are now all at risk of falling apart, is probably the hardest of all.

I was there to hold my own mother's hand and that of my best friend, Wendy, in the last days and hours of their battles with cancer, but nothing can prepare you for the gut wrenching strength you will need to advocate for, support and care for your child.

I am hopeful that something in this book will be of help... even one tip, action or piece of advice, I am hoping it gives you HOPE.

Hope is everything. It is the light at the end of the tunnel. You just have to believe it is there, then one day you see a flicker and step by step, paso a paso, breath by breath, you walk towards it. One day you will feel the embrace of the light and live again in the light. One day... I don't know how long that will take you... I am only now just feeling, after 9 years since diagnosis, that we are back in the world of light. I can only hope you get there sooner.

I know right now it feels so dark, full of fear and where is the hope? The hope is in every breath and in every moment. Keep going onwards in the darkness with blind faith and hope. What choice do you have? You will instinctively fight for survival alongside your warrior.

This book was born out of one question, asked by our incredible Cancer Nurse Specialist (CNS), Filippo,

after our son Ramsey's bone marrow transplant (BMT) in London during 2019 after 2 years of an Intensive chemotherapy protocol in Spain which started on the 21st of April 2016.

"So, what did you do?" he asked. "What did you do that meant he could leave the hospital early post transplant and more importantly, not come back with a secondary infection?"

Statistically, post-transplant, "up to 75% of patients have at least one significant infection after transplant." - Ref 82 "Seminars in Pediatric Infectious Diseases" Vol II, Issue I, pages 59-67

During any chemotherapy or radiation protocol a secondary infection is a huge cause for concern. The immune system is so weak and ineffectual it can make the patient highly vulnerable and open to any infection in any area of the body. These are the infections that can be hard to treat when the body is so weak and fragile. The name prescribed to this depletion of the immune system is neutropenia, when the neutrophils are so low the white blood cells of the immune system are barely able to function and fight any infection.

We did not return with a secondary infection and Filippo had clearly noted this. He had seen the hospital rooms we stayed in, he had seen how we managed the space. He knew we were going against the odds and wanted to let us know that in all the complimentary health support we gave, we were doing something that he felt was worth sharing.

So here I am, daring to act upon the request this angel of a man asked of me. This is not because we have been given remission but because we feel "off the leash" as we are no longer, for the first time since diagnosis in 2016, going to hospital for daily, weekly or monthly blood tests or treatment anymore. Maybe the

news that we did not have to go back for regular treatment has allowed me to dare to breathe and to share.

Important Medical Context: Let me just explain that I hope your diagnosis and protocol is nowhere near as aggressive as the one we followed and now less than a decade later I am reading that there can be alternatives to this protocol which are far less brutal, thanks to the introduction of tyrosine kinase inhibitors (TKIs) and blinatumomab, the need for such aggressive chemotherapy protocols has decreased and survival rates have improved dramatically.

The protocol in Europe that we followed was 2 years of treatment (with breaks for when the patient is too sick to receive treatment this means the time scale can vary and be up to three years. In Australia for young males with ALL Ph+ the protocol is 3 years.) The treatment means you are often in hospital for 3 week stints but of course this can be longer and when you get a fever it is until the fever abates and treatment can continue.

So unlike many other forms of cancers and sub categories of Leukaemia, this protocol is one of the most aggressive chemotherapy and steroid based treatments due to the high cell replication when you are an infant and a teenager. The rate of killing cells has to be high due to the fact it is all over the body (even passing the blood brain barrier) so it invariably has devastating long term health impacts on those that survive. Thankfully the future looks brighter for anyone diagnosed in more recent years.

Important Disclaimers:

- This guide complements, never replaces, medical care
- All complementary approaches should be discussed with your medical team
- Every child's journey is unique—adapt these

strategies to your situation

- When in doubt, always consult your healthcare providers

Please allow me to state that this book is not a medical manual - it's a lived experience. It's the things we did as parents and carers. It is the battles as a mama bear, I quietly (and sometimes not so quietly) fought; the things in the hospital we questioned and what we sought out to replace them with; the environments we created, the intuition we trusted, the boundaries we held.

PART I: THE JOURNEY

Chapter 1: When Your World Changes

“Step by step, Paso a paso” became the mantra I fitted my breathing pattern to.

INHALE.. step by step

EXHALE..paso a paso.

The steep learning curve you encounter when you enter a cancer hospital, from new terminology to medicine names and stages of a protocol can literally take your breath away.

INHALE....step by step

EXHALE...paso a paso

Take it all one step at a time. Write down as much information as you can take.

Take it a step and a breath at a time.

There are times when you have to just inhale and exhale to make sure you are still present and this is really your body, your life, your today.

Coming from a family of war veterans, I have likened being at the side of your child as they fight for their lives like being in the trenches with your son during the world wars. My grandmother did not know what her husband in the First World War and her son in the

Second World War were truly experiencing. They heard snippets of news on the radio, in a letter, maybe from their loved one in person occasionally. We were there (my husband and I alternated every 48 hours being at Ramsey's side until we were too exhausted and had to go down to every 24 hours) having a front row seat in the trenches with my son.

We watched as he fought, sometimes for his life. Pushing him on a trolley 23 times for general anaesthetic so he could have chemotherapy sent up his spinal column and past the blood brain barrier (Intrathecal.) Waiting to see when they would call our name to push him back to the ward, or when he would arrive on the ward, when he would come around and how would he be? Would we be on the ward again, in an isolation room or allowed to go home for a few days? Day after day, week after week, month after month to complete this 2 year protocol, when they would tell us if he was cancer free ...if he could even survive that long? Gripping on to survive ...just breathe Kay, just breathe.

I watched and listened and learnt as much as I could in this environment. I learnt to feel his skin for fever, one of the first lessons you learn. You learn to stay alert even when your own body is begging for sleep. There is no "off switch" as any carer knows, when you are advocating and fighting for your warrior's very survival. This level of hyper vigilance and fear a parent carries is often a cause of chronic adrenal fatigue and stresses within the mind and body.

I do not write this with arrogance or certainty. I write it with humility and love. This is what we tried and what has worked for us,so far.

If anything in these pages can help one other person - one child, one family - then Filippo's question is validated.

You don't have to go through this alone. I hope this book becomes a guide, a beacon of light amidst all the

lack of control and uncertainty that a cancer diagnosis contains.

Taking It Step by Step

Your First Week Survival Strategy:

- Write down everything—questions, observations, medication names, nurses, doctors and consultants names.
- Take one piece of information at a time
- Use your breathing technique when overwhelmed
- Remember: you don't have to understand everything immediately
- Find one person on the medical team you trust and connect with them - this could be your CNS or anyone who is specifically assigned to you and your case.

Key Questions for Your First Medical Meeting:

1. What exactly is my child's diagnosis and stage?
2. What does the treatment protocol involve?
3. What are the most common side effects?
4. Who is our primary point of contact?
5. What emergency signs should we watch for?
6. What can we do to support health and healing alongside treatment?

Chapter 2: Immediate Self Help Modalities

Connecting with yourself. Breathing Exercises.

Sit with your left hand on your heart and your right hand on your abdomen.....BREATHE.

Breathe in deeply into the hand on your abdomen and exhale a deep slow sigh.

You can exhale through your mouth like a sigh, to surrender. You can exhale through your nose too, this is better for when you have already sighed the deep surrender breathes out. Nasal breathing if you can, but don't worry if the sigh through the mouth seems easier. Just whatever feels right now.

Inhale, two three, four, ...suspend
Exhale, two, three, four, five..pause
Repeat.

Repeat as often as you need as often as you can.

Use counting, use my mantra, use your own mantra to fit to your breathing pattern in order to slow it down.

This is the best advice for calming your nervous system and realising you are present.

Breathing is the key to your parasympathetic nervous system and will help you keep as stable and be healthy as you can when all you want to do is run and escape this diagnosis and this madness.

Full inhales and long slow exhales. Keep reminding yourself. Keep checking yourself using your hands to feel yourself dragging air in and if you can't find the air in the room go outside or open the windows if you can.

Find the air, find your breath and connect to your nervous system knowing you are doing the best you can right here right now.



Breathing Techniques

These breathing techniques are proven to regulate the heart rate, calm the mind and therefore reduce stress levels. We are capable of leading ourselves into a parasympathetic state of being and thus not being in “fight or flight “ mode. Through using any or all of the below breathing techniques we are capable of reducing cortisol surges and chronic states of hyper-vigilance. We need to be able to do this to be a more effective carer.

Diaphragmatic Breathing (Daily Foundation) - as described above

- Place one hand on chest, one on belly
- Breathe so only the belly hand moves

This activates the vagus nerve and calms the nervous system

4-7-8 Breathing (For Acute Stress):

- Inhale for 4 counts
- Hold for 7 counts
- Exhale for 8 counts
- Repeat 3-4 times maximum

Box Breathing (For Focus and Clarity):

- Inhale for 4, hold for 4, exhale for 4, pause for 4
 - Visualise drawing a box as you breathe
- Use before important medical conversations

Breathing techniques focused on extended exhalation, slowing down the breathing (ideally to 10 breaths per minute or less), holding the breath briefly, and then exhaling have all been shown to slow down the heart rate. The magic is in the exhale.

Common feelings after breathwork include feeling

more positive and alert, and less aroused by stressors. Research has shown that slower breathing increases alpha activity (brain wave activity associated with a relaxed and focused state) which are of great help when you are struggling to keep focus and make decisions.

Breath control will benefit you enormously.

Chapter 3 :The Learning Curve

“One day you will tell your story of how you overcame what you went through and it will be someone else’s survival guide.” — Brene Brown

There is no manual for this. No checklist that tells you how to survive when your child is fighting for their life. But over time, you begin to find fragments, small things that keep you from falling apart completely. These were ours. Not perfect, not always pretty, but they helped.

It’s about being a vigilant, loving, exhausted, fierce advocate . You are not only a parent, but a carer, a protector, a seeker of help and knowledge, another pair of eyes in the dead of night to help the nurses when the treatments continue and the monitors beep endlessly.

The hospitals in Spain and the UK were full of extraordinary human beings, and yet I still had to stand my ground against some of the standard procedures and practices that are in place in these institutions. Knowing you have the right to question certain procedures gives you more control of these often brutal situations and treatments. Having even the right to bring in your own food or pillow or blanket can make all the difference to you and your child.

You will be able to have these things in some cancer protocols or hospitals but maybe not in others. You have to be able to ask why and think what you need to do in order to support your child. With a cancer protocol you hand the body of your child over to a brutal protocol but you also have the right to maintain some of your beliefs of what health and complementary health care looks like to you. You know your child and

see the changes in the skin, eyes, mouth, postures, energies more than anyone. You can help the health care providers with all this information you have.

Becoming a Medical Advocate

Essential Documentation System:

- Keep a daily log of symptoms, medications, and observations
- Photo-document any concerning changes (rashes, mouth sores, etc.)
- Track patterns in energy, appetite, and mood
- Note questions as they arise, don't trust memory during stress

Building Relationships with Medical Staff:

- Learn names and introduce yourself as a partner in care
- Acknowledge their expertise while asserting your parental insights
- Small tokens of appreciation go a long way in letting these professional carers know how much you value them
- Be the parent who makes their job easier, not harder

Understanding Your Rights as a Parent

You have the right to:

- Question any procedure or medication
- Request second opinions
- Bring comfort items from home (within safety guidelines)
- Be present during most procedures when your child is a minor
- Request specific staff members when possible
- Advocate for your child's comfort and dignity

PART II: PRACTICAL SURVIVAL STRATEGIES

Chapter 4: Creating Healing Spaces

Make the room a sanctuary.

Hospital rooms can be clinical, cold, chaotic. I started to bring things from home — essential oils and a diffuser, a small salt lamp, soft throws, calming music. It wasn't about pretending we weren't in a hospital. It was about reminding myself and my son that we had some control of our health and well being even in the most unfamiliar of places.

Our hospital room, which could have smelt of vomit, bleach, fear and sadness, became different. Nurses and doctors often walked in and said, "This room feels peaceful. It's our favourite one to visit." They didn't know exactly why—but I did. It was the scent. The care in the air. The energy we'd created.

Hospitals are rarely where you heal, the healing happens in the home. However if you are there for weeks and months at a time you have to create a healing environment.

When you can't get out into the forest bring it into your space. For us our essential oils diffuser gave us structure to the day.

In a morning I would diffuse citrus oils such as Sweet Orange or Bergamot with a grounding oil such

as Frankincense or Atlas Cedarwood.

In the afternoon or early evening I would change to Lavender with Frankincense or Cedarwood or Vetiver. These essential oils are all deeply relaxing and calming to the nervous system.

When Ramsey had neutropenia I would diffuse “Thieves” a blend of herb and spice oils that was used during plagues. Its high anti bacterial, anti microbial, anti fungal properties made it ideal for when his immune system was compromised.

Why was this area of complementary health care so important to us? Hospitals smell of fear. Chemotherapy creates nausea. The bathroom is next to where you live, fight and sleep and you can be there for weeks at a time.

Scent not only masks all the above but essential oils have natural healing properties that mean when you are trapped inside the healing energies of plants and trees can still give you a sense of well being and being outside in nature.

When you can get out - get out to the trees. None of this is unscientific it is prescribed in Japan under the name of “Shinrin Yoku” or translated as Forest Bathing. Since Covid getting out in nature and recognising the healing power of the chemical emissions plants have to heal humans is more commonplace in the West.

Essential Comfort Items:

- Aromatherapy diffuser with gentle oils (check hospital policy first)
- Morning: Sweet orange + frankincense for energy and grounding
- Afternoon: Lavender + cedar wood for calm
- During times of weekend immune system you can use: “Thieves” blend for antimicrobial properties (recipe on page 57)
- Soft lighting: Small salt lamp or battery-operated

string lights

- Familiar textures: Soft throw blanket, favourite pillowcase
- Calming sounds: Downloaded music, nature sounds, or white noise
- Visual comfort: Small photos, inspiring quotes, or meaningful objects

Scent Strategy: Hospital smells can trigger nausea and anxiety. Essential oils serve multiple purposes:

- Mask medical odours
- Provide therapeutic benefits (lavender for calm, peppermint for nausea)
- Create positive associations with the space
- Help staff feel more comfortable in your room

Infection Control with Comfort

Your Hygiene Protocol:

- Hospital-only slippers that never touch corridors. use separate shoes you change into for corridors and the outside world.
- Hand sanitiser with 70% alcohol minimum
- Personal cleaning supplies for surfaces
- Fresh bedding as often as allowed
- Air circulation whenever possible
- Wipe down all screens daily, plus control panels.

Creating Sacred Space: Even in isolation rooms, you can create atmosphere:

- Use battery-operated candles for ambiance or a salt lamp which can also clean the air when plants are not permitted.
- Play soft music during treatment times
- Establish quiet hours for rest
- Create a “comfort corner” with special items the patient enjoys. Keep all toys and games that are

easy to wipe down or wash frequently.

Movement and Physical Therapy

Bed-Based Exercise Routine: When mobility is limited, gentle movement maintains circulation, prevents blood clots, and supports mental health.

Movement is really important for cancer patients but sometimes they can't leave the room or stand for long so a bed routine is essential. Walking the corridors is actively encouraged in hospital and walking as an outpatient is really one of the best forms of movement for a cancer patient. However some days walking in the corridors or outside is not the best option when the patients immune system is weak or there is a higher chance of infection by leaving the room or home.

This is why as a movement therapist and Pilates teacher of many decades, I was able to make a simple routine for not only my son but also for a friends mother whilst she was in hospital.

The following exercises are a basic routine that you can build upon. You can add resistance in the form of using your own hands to create resistance for the patient or you can introduce bands and small weights if that is required. Just make sure you can always easily clean any lightweight equipment you are using.

Exercises such as:

- Ankle circles and pointing/flexing the ankle joint
- Knee bends and extensions slightly raised off the bed if possible so that means you have to use the core muscles too
- Knee at 90 degrees and some circles in the air in both directions
- Straight leg lifts and lowers. You can add the resistance of the carer's arms pressing down as the patient tries to lift to give more strength

training to the movement

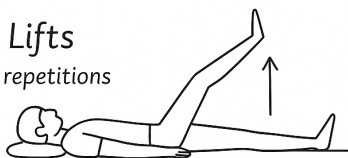
- Wrist circles
- Arms up and down overhead
- Arms punching across the body
- Big arm circles in both directions
- Head turns East and West (Right and Left), North and South (Up and down)

5 fundamental exercises for in bed and when you are standing by the bed.

Bed Exercises

Leg Lifts

5–10 repetitions



Knee flexes/ extensions

5–10 repetitions



Ankle circles

5 in each direction



Hip circles

5 in each direction

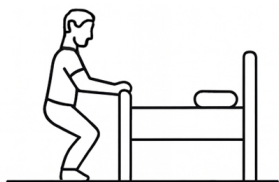


Controlled spinal lifts

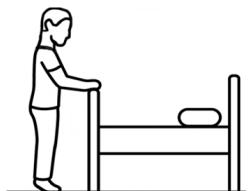
Try to curl up
one vertebra at a time
Hold and squeeze your buttocks.
Slowly lower down



Standing Exercises



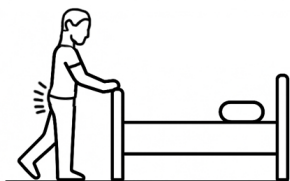
Parallel leg
squats
× 10



Calf raises
× 10



Side leg lift
× 10



Leg lift,
squeezing buttocks
× 10



Balance
5-10 seconds

“Structured exercise has been shown in pre-clinical studies to reduce the growth of cancer. In addition observational studies have shown that patients who perform an increased amount of recreational physical activity after treatment have a lower risk of cancer recurrence and mortality. Possible mechanisms for these associations include the effect of exercise on metabolic growth factors, inflammation and immune function” - NEJM, July 3, 2025.

During treatment in Spain and again post BMT in the U.K we managed to get hold of bicycles. The first time the school my son attended fund raised for an electric bicycle when he was very weak and the second time we were gifted from “Cyclists for Cancer” a new push bike. We did return both bicycles to the shops for other people to get the benefit from as Ramsey did not really manage well on bikes, but I know many many children and young adults truly benefit from cycling. This way of moving without stressing the joints gives great cardio vascular benefits, but also its freedom and a sense of fun.

Chapter 5: Food as Medicine

Food is medicine.

It didn't take long for me to realise that the food presented in the majority of hospitals is not for healing. To keep the risk of infection low the food is often given a bleaching process to remove any micro bacteria and then is heavily overcooked or microwaved and wrapped in plastic and served on plastic and you are given plastic cutlery. It's not easy to smell or taste it and although we tried in the early days it was one of the first things I began to kindly refuse.

If I was refusing hospital food what was I going to replace it with and how?

I knew how critical nutrition was, especially when his body was being broken down so rapidly by the chemo. By the way, you may encounter hospital staff who will say that because the body is being poisoned and cells killed daily that it doesn't matter what you feed a cancer patient but of course this is only one school of thought. It is a school of thought that we did not prescribe to, but again this is your choice.

With no facilities to make food I found the support and strength and guidance of those who could. Nutritional support from Francesca Hillman - a traditional Chinese medicine doctor - who made him bone broth and nourishing soups when we could not physically get into a kitchen was vital in those early months. The bone broth was nutritionally dense and healing to all the inflammation that would be taking place along the whole digestive tract from the sores in the mouth all the way into the stomach lining and to the anus.

When we were told no outside food could be brought in as the risk of infection was no longer un-

der their control, I found a couple in the UK who were making dehydrated bone broth and got them to send it over. This way I could take my collapsible travel kettle into the hospital and make him a fresh cupful to sip when warm through a straw.

Fresh juices had to wait until we knew he was stronger and could take raw uncooked fruits and vegetables as there are more microbes and natural bacterias present. Wrapped fruits like bananas & oranges better than grapes or apples when the skin is open to the elements. So peel the apples, peel the grape if you have to!

The Feeding Tube Decision

Trusting your instincts when you are yourself fragile and exhausted is not the easiest of asks. However you are advocating for what you think is correct for your child and sometimes you have to question and fight for what you think is correct. One example of this is why I did not wish for him to be fed through a nasogastric tube.

At this point Ramsey's mouth was full of sores and he found it difficult to swallow. He had bleeding and protruding piles, so going to the toilet was difficult too. I imagine that from the mouth all the way down his digestive tract and his stomach and his bowels were all inflamed and full of sores. He was effectively an open wound on the inside and the thought of pushing down a plastic tube I thought may bring more discomfort and also possibly cause more internal wounds. This was what I felt, it was never shown to me or proven by discussing with nurses or doctors, as for them it was the "norm" to tube feed at this point.

What I did research was what food is put down the tube? It is like a mashed potato formula typically containing a mix of carbohydrates, proteins, fats, vitamins,

and minerals. It is man made and will keep you alive but will it bring about the best healing?

I again listened to instinct and said we would try to find liquids ourselves to give him the best nutrition we could. We had been doing this in Spain from the very start with bone broths being prepared by Francesca with organic animal bones and at certain times adding galangal, turmeric and healing herbs.

Practical Nutrition Solutions

The Bone Broth Solution: I went on the internet to find a company based in the UK that was making dehydrated bone broth and found a starter company, husband and wife in Newcastle, who were able to send me dehydrated packets so I could use safely in a hospital environment.

Alongside this we had electrolyte sachets to add to clean filtered water helping to keep the body optimally hydrated. Stewed apples, mashed banana, mashed avocado, little by little a teaspoon here a teaspoon a bit later. Gently drinking the warmed bone broth and taking in natural foods that were nutritionally dense.

Emergency Nutrition Kit:

- Collapsible travel kettle for hot water
- Dehydrated bone broth packets
- Electrolyte packets (low-sugar options)
- Easy-to-digest snacks: dates, bananas, home-made oat flapjacks
- Herbal teas appropriate for treatment phase

Not to forget ready made nutrient dense drinks that the hospital may offer or can be bought in most health food stores.

One thing for sure hospital food is ultra processed and full of sugar, hidden sugars. In the little pots of yo-

ghurt they gave the children to come around post anaesthesia, there are up to 8 teaspoons of sugar. They even offer sugar soda drinks! Yes it's easy and yes the sugar is effective but there are alternatives to bring the patient around post treatment.

We packed for example some dates, a banana or a homemade oat flapjack, with added ground flaxseeds for Omega 3 and to help with a sluggish digestive system. Whatever you can do, try to find healthy liquids and easy to eat snacks that your patient likes for post surgery and treatment.

So yes you may go against hospital guidelines and provisions but you sometimes you may have to. Keep listening inwards.

The Reality of Hospital Food

Common Issues:

- Over-processed and sterilised to prevent infection
- High in hidden sugars and preservatives
- Served on plastic with plastic utensils
- Often lacks appealing smell, taste, or texture
- Limited options for dietary restrictions
- When to Consider Alternatives:
- Your child consistently refuses hospital food
- Severe mouth sores make eating difficult
- Digestive issues from treatment
- Significant weight loss
- When medical team suggests feeding tubes

Nutritional Strategies by Treatment Phase

During Intensive Treatment:

- Focus on liquids: bone broth, electrolyte solutions, herbal teas
- Soft, easy-to-digest foods: mashed banana,

- stewed apples, avocado
- High-calorie, nutrient-dense options when appetite allows
- Avoid raw foods during neutropenia (low immune system periods)

Recovery Phases:

- Gradually introduce raw fruits and vegetables
- Choose wrapped fruits (bananas, oranges) over exposed ones (grapes, apples)
- Focus on anti-inflammatory foods
- Support gut health with appropriate probiotics (consult medical team)

Practical Implementation

The Bone Broth Solution: When solid food becomes impossible, nutrient-dense bone broth can provide:

- Essential minerals for healing
- Protein for maintaining strength
- Collagen for digestive tract repair
- Warmth and comfort

Working with Medical Resistance

When hospitals say “no outside food”:

- Ask to speak with the nutritionist
- Request written policies about outside food
- Discuss specific nutritional concerns with your medical team
- Propose compromises (sealed packages, specific preparation methods)
- Document your child’s/patients nutritional decline if the hospital says no to outside food during transplant.

Advocating for Nutrition:

- “My child hasn’t eaten in three days. What alternatives do we have?”
- “The feeding tube feels traumatic. Can we try nutritional liquids first?”
- “What are the actual infection risks vs. malnutrition risks?”

Chapter 6: The Art of Advocacy

Being your child's advocate means becoming comfortable with being uncomfortable. You'll need to question procedures, challenge assumptions and sometimes go against hospital protocols, all while maintaining collaborative relationships with the medical team.

Standing Your Ground

The following are **examples** from our experience alone. You will have your own concerns and battles. I write these examples purely for you to feel you are not alone and for you to feel supported in the instincts you will have throughout your hospital experiences.

The Cleaning Protocol Battle

Another battle was with the cleaning of rooms in the UK. In Spain a fresh bucket of water with bleach was how each room was cleaned twice a day.

In our UK hospital I saw the cleaner drag a bucket of water from the room of the boy next door into our room and she was about to start mopping! You cannot have the dirt and bacterias of one sick room dragged into another when the patient has a low immune system or is neutropenic. She did not speak English so I somehow managed to explain that it was supposed to be a clean bucket of hot water and bleach for each room otherwise I would do it myself and of course I was already doing it secretly wiping every surface multiple times a day with anti bacterial wipes and using my essential oil surface cleaners.

The Shoe Cover Confrontation

It is the same with how doctors and consultants

walked from the outdoors streets bringing all that dirt with them into the hospital wards. In Spain the nurses change into paper clothing and have their clogs placed in a bleach bath each day. The paper clothing is then incinerated and the clogs are thus sterilised. If everyone is doing this and you as a carer, change shoes from outside the hospital to inside the room each time you go in and out, you are daily keeping the environment as safe as possible.

So when I ask that anyone entering the room puts on plastic covers on their outdoors shoes I am met with a sharp “no this is not necessary”. Eventually they send down the hospital virologist to speak to this “crazy mama bear” and explain about germs and the hospital codes of conduct, however I feel I have the right to ask if for my sanity and for the health of my child all that is needed is to pop on the blue shoe covers which I had already provided and placed alongside the masks and aprons that are in the entrance vestibule beside the sinks in each isolation room.

It caused me to have a reputation as “over obsessive” one might say, but hey! that’s fine by me as I need to be when advocating for the health of my child no?

It was upsetting to be like this, of course I was highly strung, but they did in both instances, for the majority of the time allow me these graces.

I write these examples of refusing the nasogastric tube, asking the cleaners to do the room effectively and safely, and the encounter with the virologist, so that you too feel and know you have the right to question. The right to question what is often taken for granted in the huge machines that hospitals are, whether private or run by the National Health Service.

You have the right to listen to your instincts when you are the carer for someone. You have the right to advocate for their highest well being. You have the

right to ask questions and make informed decisions.

Effective Advocacy Language

The Collaborative Approach

- Frame concerns as partnership: “I’m noticing... what do you think?”
- Acknowledge expertise: “I know you see this often, and I see my child daily...”
- Propose solutions: “What if we tried... would that work within your protocols?”
- Document everything: “Can we note this conversation in the chart?”

Daily Advocacy Checklist

- Try to talk daily with nursing staff about today’s plan
- Clarify any new medications or procedures
- Communicate any overnight observations
- Ask about timing for procedures and treatments
- Confirm comfort measures are in place

Standing Your Ground on Key Issues:

Example 1: Refusing Feeding Tubes Situation: Medical team wants to insert feeding tube due to poor oral intake.

Advocacy approach

- “I understand the concern about nutrition. Can we try liquid nutrition for 48 hours first?”
- “What specific nutritional markers are you most worried about?”
- “If we can maintain hydration and some caloric intake, can we avoid the tube?”
- “What signs would indicate we absolutely need the tube?”

Example 2: Cleaning Protocols Situation: Cleaner brings same bucket from previous room. Advocacy approach:

- “I noticed the cleaning bucket came from another room. With my child’s compromised immune system, could we have a fresh bucket?”
- “I have my own cleaning supplies if that’s easier.”
- “What’s the hospital policy on room-to-room cleaning during neutropenia?”

Chapter 7: Emergency Preparedness

Cancer treatment is unpredictable. Having systems in place for emergencies reduces stress and ensures you're prepared for rapid changes.

We kept a bag in the car at all times—our emergency overnight bag. Inside: a small diffuser, a few oils, a travel kettle, sachets of dehydrated bone broth, herbal teas, a notebook, a good scarf, a pair of socks, lip balm, earplugs, and sometimes, a tiny photo of the sea. Little anchors to normal life.

The Ultimate Hospital Go-Bag

Comfort & Care Essentials

- Soft scarves, hats, head coverings
- Warm socks and hospital-only slippers
- Sleep mask and earplugs
- Lip balm and moisturiser (unscented and as few ingredients as possible.)
- Individual eye drops (separate bottles for patient and caregiver)
- Familiar blanket and pillowcase
- Your and your patient's room slippers
- Health & Soothing Tools:
- Digital thermometers and under tongue thermometers
- Gua-sha tool (*I was taught by Francesca Hillman TCM doctor about how to perform gua-sha to take the heat out of the body by scraping down either side of the spine from the nape of the neck to the bottom of the spine. It was scary as he was so weak and skinny and bony but it was worth a try and guess what..it worked! It*

worked the three times I performed it and meant one less drip and drug infusion.)

- Instant cold packs or reusable ones
- Carrier oil for foot massage (grape seed, almond, olive, no topical essential oils when the patient is undergoing chemotherapy is the safest call.)

Food & Nourishment

Our own kettle so I didn't have to keep leaving the room and touching other equipment or exposing myself to others in communal areas. I used a collapsible travel kettle specifically for this purpose.

- Box of snacks: nuts, seeds, dates, dried fruit
- Electrolyte sachets or drinks
- Herbal teas
- A spoon, fork, bowl and paper straws

Car Emergency Kit

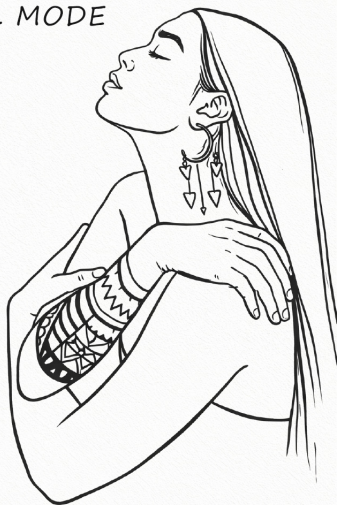
Always Keep in Vehicle

- Sick bags and cleaning supplies
- Extra blanket and pillow
- First aid kit
- Phone car charger
- Bottled water and shelf-stable snacks
- Change of clothes for both patient and caregiver
- Cash for parking and emergencies
- Entertainment (downloaded movies, books, games)
- Vehicle Maintenance:
- Keep gas tank at least half full
- Check air conditioning/heating systems regularly
- Replace cabin air filters frequently
- Consider car air purifiers during high-risk periods

PART III: SELF-CARE FOR THE WARRIOR PARENT

Chapter 8: Caring for the Caregiver

*I FORGIVE MYSELF FOR
WHO I WAS IN
SURVIVAL MODE*



You may not be the best version of yourself right now as you walk through this pain. You will lose people who you thought were friends & even some family members will not be able to support you in the way you need.

Keep your circle small and full of warriors who can be there through the ugly times & still fight at your side.

Then later - maybe or maybe not - you will be able to forgive yourself and others for who you were in survival mode.

One thing for sure those who stood at your side are true angels and that version of you was the best you could be at that time.

You show up as a warrior parent/caregiver day and night..the strength comes from within. The strength comes from all the mothers praying for you, holding a light up for you, for the mothers and grandmother warriors who have fought their fights before you. It is all within you. There is a deep well of strength from all the mothers you have come from..they are there pushing you forwards in this fight and holding you up when you think you can't go on.

Essential Self-Care Strategies

Rest, when and where you can. It's not just about sleep, it's about micro-rests. A few deep breaths in the corridor, sitting in the sunlight. Closing your eyes for two minutes and saying, "I'm still here. I'm doing my best."

Eat really well when you can. You may not have regular meal times or a regular diet (I lived on tortilla drizzled with extra virgin olive oil for every meal in hospital in Spain where a gluten free vegetarian is not easy to cater for!) but when you do get the opportunity to eat or shop buy the best possible versions of whatever you fancy that truly can nourish you.

Breathe in this power from all the support and love surrounding you. Around the clock there is someone in this world sending you unconditional love and strength. Your friend in Nicaragua, your family in Australia, other parents you connected with on a blog in America, cousins who live in Japan.....all over the world, every hour of the day someone is sending you unconditional

loving strength and it has the power to heal.

Ask for help and accept offers of help. This one was hard for me, but I learned when someone offered to bring food or take my other son away to enjoy himself for a few days, I eventually learnt to accept the offers.

If someone offers you a free blow dry or haircut, take it. It will make you feel so much better. If your boss says take extra time off..take it.

If you are self employed you will probably need fund raisers or charities to help you. We sold our home and lived at our in-laws so that is the choice we made. We needed the support of a home for our eldest son who was studying for his Baccalaureate but also we needed the money as we received no government support in Spain as self employed individuals and we both took the first year off work to care in shifts for Ramsey. In the second year it was only my husband who could work and I could earn or claim nothing in Spain. So we lived off and spent our house savings on getting help from outside sources.

The Reality of Caregiver Stress

Physical Impact

- Chronic sleep deprivation
- Stress-related illness and weakened immunity
- Adrenal fatigue from sustained hyper vigilance
- Poor nutrition from irregular eating
- Physical exhaustion from hospital schedules

Emotional Toll:

- Anticipatory grief and constant fear
- Isolation from normal social support
- Relationship strain with partners and other children
- Loss of identity beyond “cancer parent”
- Survivor guilt when things go well

Non-Negotiable Self-Care Strategies

Micro-Rest Techniques

- Two-minute breathing breaks between hospital visits
- Sunlight exposure whenever possible—step outside, sit by windows
- Mindful transitions—conscious breathing when moving between spaces
- Bathroom breaks as meditation—the only private space available
- Car sanctuary time—sit quietly before entering hospital or home

Nutrition for Survival: When regular meals become impossible

- Emergency nutrition kit: nuts, seeds, protein bars, electrolyte drinks
- One good meal strategy: When you can eat, make it count nutritionally
- Batch cooking: Prepare meals when you have energy, freeze portions
- Support network meals: Accept all offers of food preparation
- Hydration priority: Dehydration worsens everything—carry water always

Sleep Strategies

- Power naps: 15-20 minutes can restore clarity
- Sleep hygiene: Even in hospitals, maintain bed-time routines
- Tag-team approach: If partnered, alternate over-night stays
- Sleep aids: Earplugs, eye masks, white noise apps
- Professional help: Don't hesitate to ask doctors about sleep aids

Building Your Support Network

Inner Circle (Immediate Support)

- Partner or co-parent
- One trusted family member
- One close friend who “gets it”
- Primary childcare backup for siblings

Support Circle (Extended Help):

- Meal delivery coordination
- Transportation assistance
- Household management
- Sibling activity coordination
- Pet care arrangements
- Professional Support:
- Primary care physician for your health
- Mental health counsellor experienced with medical trauma
- Spiritual advisor if relevant to your beliefs
- Support groups (online or in-person)

Financial Survival Strategies

Immediate Needs

- Apply for all available assistance programs
- Contact hospital financial counsellors
- Research cancer-specific grants and foundations
- Set up crowdfunding if comfortable
- Negotiate payment plans for medical bills (if that is required.)

Long-term Planning

- Understand disability options
- Communicate with employers about flexible arrangements

- Connect with social workers at treatment centres
- Consider relocating temporarily if needed for better support or treatment

Money-Saving Hospital Tips

- Pack meals and snacks to avoid expensive cafeteria food
- Use hospital guest house programs when available
- Take advantage of free parking programs for families
- Use hospital wifi instead of data
- Accept gift cards and practical donations

Chapter 9: Mental Health and Resilience

Protect your mental space. Limit your time online. The internet is a blessing and a curse. Yes, research is important but doom-scrolling can spiral you into panic. Choose one or two reliable sources. Maybe one Cancer support group that is specific to the diagnosis so you can learn from others in other countries and keep informed. Also a good support group will understand when you need to pause and step away sometimes when it all gets too much.

Finding Your Grounding Practices

Find small rituals of grounding, for us it was diffusing essential oils. Breathing with my hand on my heart and belly so I knew I wasn't just shallow breathing all day long. Writing a single sentence in a journal or pouring my heart out into it. Anything that reminded me I was still here, still human, still a mother, even when everything else I had in my previous life was no longer there.

Grieve what you've lost — Fight for what remains

You are allowed to grieve. The life you had. The plans. The normality. There is no shame in missing your old world while living inside this one. Acknowledge that pain. Let the tears come when they need to. And then — return to the fight.

Staying Connected to Your Inner Self

I said earlier I didn't have an orthodox religion but that doesn't mean I had no grounding.

My father handed me a yoga book when I was 14 years old and that was the book that introduced me to breathing techniques - Pranayama - and I instantly felt the effects in my mind and on my body. Over the years, I'd sought out teachers, mentors, practices that connected me to something deeper, something steady.

When the chaos of cancer treatment came, I brought that with me. Literally I brought my yoga mat into the hospital.

I didn't roll it out for a full practice or a headstand. Sometimes, it was just a space to breathe. A full breath in, a full breath out. That's all. And when I sat there on the mat in the corner, it wasn't just for me. It was for Ramsey too. He needed to see that Mum was still Mum. That there was still a thread of her normality in the madness.

Another mother once looked at me and said, "You look dreadful. Put on some lipstick." Lipstick? Really? But then I realised it wasn't about vanity. It was for our kids. To see that we hadn't let ourselves fall completely apart. That we were still standing. So yes, some mornings I put on lipstick, not because I wanted to, but because it helped Ramsey see me as more than the shell of a frightened, exhausted mother.

I saw this in others too. A father with deep Christian faith brought his guitar to the ward. He'd play and sing, softly, and I thought why is he playing songs in a cancer ward? But then I saw it. His son saw his dad as he'd always known him: strong, faithful, musical. That's what held him up. That's what gave him strength.

So whatever it is that keeps you feeling whole, whatever helps you stay tethered to yourself, bring

it with you. Whether it's a yoga mat, a guitar, knitting needles, prayer beads, lipstick, or your favourite book. Whether it's your faith, your rituals, your music, your methods of breathing. Use it.

Understanding Trauma Response

Normal Responses to Abnormal Situations:

- Hyper-vigilance about symptoms and changes
- Difficulty concentrating on non-medical tasks
- Emotional numbness or overwhelming emotions
- Physical symptoms of anxiety (racing heart, digestive issues)
- Sleep disruption and vivid dreams
- Irritability and shortened patience
- Acute Stress vs. Long-term Adaptation: The first months require crisis management skills. Long-term treatment requires building sustainable coping mechanisms. Recognise which phase you're in and adjust expectations accordingly.

Cognitive Strategies for Dark Days

Reframing Techniques:

- "This is hard" instead of "I can't do this"
- "We're learning as we go" instead of "We don't know what we're doing"
- "Today was difficult" instead of "Everything is terrible"
- "We're doing our best with what we have" instead of "We're failing"

The Mental Battle Toolkit

Catastrophic Thinking Management:

- Notice when your mind goes to worst-case scenarios

- Name it: “I’m in panic mode now”
- Return to present moment: “Right now, in this moment, we are okay”
- Focus on the next step, not the entire journey (remember “Step by Step, Paso a Paso”)

Information Management:

- Limit research time: Set specific times for medical research, not all day
- Curate sources: Choose 1-2 reliable medical sources, avoid forums initially. However, a select specific group may be invaluable once you feel you are able to process the diagnosis and protocol
- Filter news: Limit exposure to medical statistics early in treatment
- Support group boundaries: Engage when helpful, step away when overwhelming

Grief and Loss Processing

What You’re Grieving:

- The life you planned for your family
- Your child’s innocence and carefree childhood
- Normal developmental milestones
- Relationships that couldn’t handle the crisis
- Your own sense of safety and control

Dreams and plans that feel impossible now

Healthy Grief Expression:

- Acknowledge losses without minimising them
- Create rituals for significant losses (ceremony for lost hair, celebration of treatment milestones)
- Journal or voice record your feelings
- Share with trusted friends who can hold space for your pain

- Seek professional help when grief feels overwhelming

Redefining Strength: Strength isn't pretending everything is fine.

Strength is:

- Asking for help when needed
- Setting boundaries with people who drain your energy
- Advocating fiercely for your child's needs
- Taking care of yourself so you can keep going

Finding moments of joy even in difficult circumstances

Building Hope Practices:

- Daily gratitude: A warm coffee, a kind nurse, a child's smile
- Future planning: Keep making plans, even if they change
- Connection: Maintain relationships that feed your soul
- Purpose: Find ways to help others when you're able
- Celebration: Acknowledge every milestone, no matter how small.

Chapter 10: Building Your Support Network

Become their advocate, fiercely and fearlessly. Doctors and nurses are incredible, but they're also overwhelmed. Systems are built for the average patient, not your child. You will be the one who notices a rash before anyone else. You will be the one who says, "This dosage doesn't feel right," or "Something's not okay." Don't be afraid to speak up. Your voice matters. There should be at least one professional on your care team that hears your voice and observations.

Managing Relationships During Crisis

Some people will disappoint you, this isn't personal, medical crises expose people's limitations with discomfort and fear.

Setting Boundaries:

- "Thank you for caring. Right now we need..."
- "I appreciate your concern. What would help most is..."
- "We're not ready for advice. We need support."

The Warriors (Your Inner Circle). These are the people who can handle the ugliness, fear, and uncertainty without trying to fix it or minimise it:

- Show up consistently without being asked
- Can sit with pain without offering solutions
- Provide practical help without expecting thanks
- Fight alongside you when needed
- Don't disappear when things get difficult

The Supporters (Your Broader Circle): These people provide specific types of help:

- Meal coordination and delivery

- Sibling care and activities
- Transportation assistance
- Household tasks and errands
- Financial support or fundraising

Professional services (legal, financial, spiritual)

The Understanders (Fellow Travellers): Other families who have walked this path:

- Cancer parent support groups
- Online communities for your specific diagnosis
- Hospital-based family connections
- Survivor families who can offer hope

Creating Update Systems:

- Group texts for close family and friends
- Social media updates for broader community
- Email lists for detailed information
- Designated spokesperson to reduce repetitive conversations
- Hospital communication book for visitors and staff
- Template Messages: For good news: “Today brought some encouraging results. [Specific information]. We’re grateful for your continued support.”
- For difficult days: “Today was challenging. [Brief description]. We’re taking it one day at a time and appreciate your patience with our communication.”
- For requesting help: “We could use support with [specific need] during [timeframe]. Please let us know if you’re available.”

Accepting Help Gracefully

Overcoming Help Resistance:

- Remember that helping you helps the helper feel useful
- Create specific ways people can contribute
- Let go of perfectionism about how things get done
- Express gratitude without feeling obligated

Helpful Help Categories:

- Immediate needs: Meals, childcare, transportation
- Household management: Cleaning, laundry, grocery shopping
- Emotional support: Listening, presence, encouragement
- Practical assistance: Insurance navigation, research, coordination
- Respite care: Taking over so you can rest or attend to other needs

Financial Support and Resources

We had support from:

- The Anthony Nolan Trust in the UK - www.anthonynolan.org
- Cyclist for Cancer in the UK - www.cyclistsfc.org.uk
- Young Lives vs Cancer (formerly known as Clic Sargent) - www.younglivesvscancer.org.uk

PART IV: MIND, BODY AND SPIRIT.

Chapter 11: Complementary Approaches

Modern cancer treatment is incredibly effective, but it's also harsh on the body and spirit. Complementary approaches can support healing, manage side effects, and maintain quality of life alongside medical treatment.

All complementary approaches should be discussed with your medical team. The goal is integration, not replacement of medical care.

Movement and Physical Therapy

Refer to the Bed Exercises section in Chapter 4 for when going out for a walk or cycle is not possible.

Traditional and Alternative Medicine Integration

Traditional Chinese Medicine Support:

Nutritional support from Francesca Hillman - a traditional Chinese medicine doctor - who made him bone broth and nourishing soups when I could not physically get into a kitchen was vital in those early months.

Energy Healing:

A huge thank you here to Joanna Sha who works

internationally as a healer and teacher on Energy healing, who worked with Ramsey for several months during treatment.

Gua-Sha for Fever Reduction:

I was taught by Francesca Hillman TCM doctor about how to perform gua-sha to take the heat out of the body by scraping down either side of the spine from the nape of the neck to the bottom of the spine. It was scary as he was so weak and skinny and bony but it was worth a try and guess what..it worked! It worked the three times I performed it and meant one less drip and drug infusion.

Infrared sauna:

We had a portable infrared sauna lent to us by Stacey from “Flawless” in San Pedro.

The benefits of an infrared sauna are manyfold and an economical version is the infrared sauna blanket if you cannot access a cabin, or portable type.

Again let me say this is what I felt able and comfortable to learn and introduce, you may well find your own tools and skills that help the patient.

Evidence-Based Complementary Strategies

Aromatherapy for Hospital Environments: Essential oils serve multiple functions in medical settings. Diffused or inhaler blend examples (note these are not for ingesting)

Antimicrobial Blends:

- “Thieves” blend: cinnamon, clove, eucalyptus, lemon, rosemary
- Tea tree and lavender combination
- Lemon and eucalyptus for air purification

Stress and Anxiety Reduction:

- Lavender for general calming
- Bergamot for mood elevation
- Frankincense for grounding and spiritual support
- Chamomile for sleep and relaxation

Nausea and Digestive Support:

- Peppermint for nausea (avoid during radiation)
- Ginger for digestive upset
- Fennel for appetite stimulation

Implementation Tips:

- Use personal diffusers rather than applying oils to skin during treatment
- Check with nursing staff about diffuser use policies
- Choose high-quality, therapeutic-grade oils
- Start with gentle oils and low concentrations

Caregiver-Assisted Exercises:

- Gentle resistance against caregiver's hands
- Passive range of motion for weak days
- Light massage to stimulate circulation
- Traditional and Alternative Medicine Integration

Traditional Chinese Medicine (TCM):

- Herbal formulas for specific treatment side effects
- Acupuncture for nausea, pain, and anxiety
- Cupping therapy for circulation (when blood counts allow)
- Dietary therapy based on TCM principles

Functional Medicine Approaches:

- Comprehensive nutritional assessment
- Targeted supplementation based on deficiencies
- Gut health optimisation

Detoxification Support:

- Infrared saunas
- Epsom salt (Magnesium) baths
- Lymphatic Drainage massages, or see an Oncology trained masseur

Energy Healing Modalities:

- Reiki for stress reduction and comfort
- Therapeutic touch for pain management
- Sound healing for relaxation
- Crystal therapy for emotional support

Medicinal Cannabis Considerations

Note: This section is for informational purposes and requires medical supervision and legal compliance.

Potential Benefits During Cancer Treatment:

- Appetite stimulation during treatment
- Nausea and vomiting reduction
- Pain management
- Sleep improvement
- Anxiety and mood support

Medical Consultation Requirements:

- Discuss with oncology team before starting (in our experience they did not wish to discuss, however this should not deter you from trying)
- Work with registered and qualified cannabis medicine physicians
- Understand drug interactions
- Monitor for side effects
- Ensure legal compliance in your jurisdiction

Quality and Safety Considerations:

- Source from licensed medical dispensaries
- Request third-party testing results
- Start with low doses and increase gradually
- Maintain detailed logs of effects
- Choose reputable suppliers with medical focus

Chapter 12: The Sound of Laughter

For a long time, Ramsey didn't laugh. Not really. Maybe a chuckle here or there watching a Mickey Flanagan clip on YouTube or something silly on TV. But the full unguarded sound of laughter? It had been missing for months and when it finally broke through again it hit me so hard I felt it in my chest. I realised I hadn't been laughing either and honestly, what did I have to laugh about?

It got to the point where I couldn't even look at families enjoying themselves. I'd see them together, relaxed and smiling, and it was unbearable. Our world had shrunk down to hospital wards, test results, and survival. We were coming to the end of a brutal two-year chemotherapy protocol, and we thought - hoped - it would be enough.

But it wasn't.

The BCR-Abl tests still showed the cancer was rumbling around his body and could re-appear at any moment. After all those agonising treatments and days and nights of chemotherapy, we were told Ramsey would need a bone marrow transplant. We searched for a match. His brother wasn't a match and so it was now in the hands of the Anthony Nolan Trust to search globally for us.

During this time we once again looked beyond the system.

The Cannabis Protocol Decision

That's how we found the Kalapa Clinic in Barcelona. It was summer, and Ramsey, sixteen years old, weighed just 43 kilos (that's under 95 pounds). His

body had been stripped down by chemo, appetite gone, energy low, his stomach unable to hold much food. We weren't just trying to fight the disease anymore we were trying to give him back some strength, and maybe a little joy.

At the Kalapa clinic we were assigned a Doctor Peguero who spoke to us at length on telephone and online calls about a medicinal cannabis protocol using CBD and THC. He explained how it could help stimulate Ramsey's appetite, ease pain, reduce inflammation, and even help with sleep. He talked us through the whole process. It sounded like something we needed to try.

We told the hospital team who had been using the chemotherapy protocol these last 2 years but they didn't want to hear it. They shut the conversation down immediately and literally covered their ears! So we understood they wanted to hear nothing about it. We were used to that, we'd already been taking our own path with food, oils, detox baths, healers, juices, trying anything that felt right for Ramsey's body. This was just one step further.

The science was there. We had read about the endo-cannabinoid system and how it works almost like a second immune system in the body. We felt that if Ramsey could start eating again, if he could laugh again, he'd feel more human. Stronger and more alive.

So we began the protocol.

The Return of Joy

I'm not saying this is the answer for everyone, it's not a cure, but for us, it gave us back something that had been missing, laughter. Real laughter and an appetite. The munchies, yes but not just junk food. We used it as an opening, a way to reintroduce nutritious, dense, healing food such as cacao brownies, thick

protein shakes with seeds, nuts, good-quality powders. We avoided fillers and additives. Everything was researched. Everything was chosen with care and advice from Francesca (TCM doctor) or from functional medicine doctors and nutritionists we were meeting online.

Laughter started to return. Sometimes from a show, sometimes from nothing at all, just a moment between us. That sound meant everything. It meant he was still in there, still fighting, still capable of feeling joy. This was the light you see in the darkness. When you feel after all he's been through and lost in the last 2 years and yet here we are, looking for a life saving donor and yet still being able to have these moments of laughter and feeling alive.

This experience reminded me that healing isn't just about medicine. It's about the whole environment: food, emotion, rest, energy, love. You build a toolkit. One piece at a time. Oils don't cure cancer. Neither do shakes, or herbs, or laughter. But together? They create the conditions for life to come back in.

You have to find what works for you, for your child, for your family. For us, it was finding ways to make Ramsey eat and to laugh. To be nourished and allowing healing to happen. That was our path. And it mattered more than I can ever fully explain.

A huge thank you here to Hanne from the Real CBD who was able to source high quality oils with provenance that we felt we could trust. To this day we still use her oils and she has helped so many people and dogs in their battles with inflammation in the body. I purposefully do not say "it helps with cancer" as Dr. Peguero informed us that a Medicinal Marijuana protocol (i.e. CBD and THC) has been found to be most clinically successful in treating Epilepsy and fits or seizures. However inflammation and stressors are the cause of most disease in the body and CBD alone can help this in many ways.

The Science of Laughter and Healing

Physiological Benefits:

- Releases endorphins, the body's natural painkillers
- Boosts immune system function
- Reduces stress hormones like cortisol
- Improves circulation and oxygenation
- Stimulates digestive function

Psychological Benefits:

- Provides emotional release and stress relief
- Creates sense of normalcy and humanity
- Strengthens social bonds and connection
- Improves mood and outlook
- Builds resilience and coping capacity

Creating Opportunities for Joy

Entertainment Strategy:

- Curate comedy shows, funny movies, and stand-up specials
- Create playlists of favourite comedians
- Find age-appropriate humour that resonates
- Encourage sharing of funny stories and memories
- Use humour apps and websites during downtime

Social Connection Through Humour:

- Video calls with funny friends and family members
- Sharing memes and funny content
- Playing light-hearted games together
- Creating inside jokes and family humour
- Encouraging visits from naturally funny people

Humour as a Coping Mechanism:

- Finding absurdity in hospital situations (when appropriate)
- Using humour to process difficult emotions
- Developing funny names for medical equipment
- Celebrating small victories with playful celebration

Supporting Natural Joy

Environmental Factors:

- Comfortable spaces that invite relaxation
- Good lighting that enhances mood
- Pleasant scents that create positive associations
- Soft textures that provide comfort
- Background music that lifts spirits

Nutritional Support for Mood:

- Foods that naturally boost serotonin
- Adequate hydration for brain function
- Blood sugar stability for emotional regulation
- Appropriate nutritional supplementation
- Timing meals to support energy and mood

Physical Comfort for Emotional Wellbeing:

- Pain management that allows for emotional expression
- Comfortable positioning for social interaction
- Energy conservation for enjoyable activities
- Sleep optimisation for emotional regulation
- Gentle movement that supports mood

The Return of Laughter

Recognising Progress:

- Spontaneous smiles and chuckles
- Engagement with humorous content
- Initiation of playful interactions
- Appreciation of others' humour
- Creation of original jokes or funny observations

Protecting Joyful Moments:

- Don't feel guilty about happiness during difficult times
- Create photo and video records of joyful moments
- Share positive experiences with your support network
- Use joyful memories as anchors during difficult days
- Recognise laughter as sign of healing and resilience

Chapter 13: Home Sanctuary Creation

Coming home should be a relief but post-transplant, home becomes a new kind of pressure. You want it to be a sanctuary, a place of peace and restoration, yet you may read or be advised: no plants, no soil, no pets. The list of risks feels endless.

We made the difficult decision to foster our cat. Not forever, but we didn't know for how long. Six months, maybe more. Stacey fostered him and although it was far from ideal, he was well cared for. I knew the risk of fungal spores in his paws, his fur. And it was the same with houseplants - gone. Their soil could harbour fungus that would be harmless to a healthy person but an unnecessary risk post-transplant.

So we had to re-imagine what healing looked like and for us that was in air, scent, light, order. The diffuser ran at home too, filled with oils that made us feel calm, rooted, held.

Cleanliness became our prayer. We decluttered. We used essential oils in cleaning. The space became about rest and healing.

I studied Aromatherapy online at this time and later in 2019/20 was able to complete a one year training in Aromatherapy and Essential Oil Blending with my teacher Suzanne le Quesne. The space became about rest and healing.

Post-Treatment Home Requirements

Infection Control Measures:

- Remove or minimise: houseplants (mould risk), pets (temporary), carpets (dust and allergens)
- Deep clean and declutter all spaces
- Install HEPA air filters and purifiers

- Use anti-bacterial, anti-mould cleaning products when possible

Establish visitor protocols and screening

- Patients Bedroom (Primary Recovery Space):
- Hospital-quality mattress protection
- Hypoallergenic bedding changed frequently
- Blackout curtains for sleep optimisation
- Essential oil diffuser for aromatherapy
- Comfortable seating area for daytime rest
- Easy-to-clean surfaces throughout

Personal items that bring comfort and joy

Bathroom Modifications:

- Non-slip surfaces and grab bars
- Separate shower space if possible
- High-quality ventilation to prevent mould
- Epsom salt bath setup for detoxification after hospital trips.
- Gentle, natural personal care products. Carrier oils such as olive, almond and grape seed. Add a little castor oil for deeper nourishment to very dehydrated areas. One family we knew used Castor Oil Packs very effectively for de toxifying the body and helping with GVHD (Graft Versus Host Disease)
- Sesame oil for foot massages is particularly good if circulation is poor
- Easy to sanitise surfaces

Kitchen Modifications:

- Water filtration system for safe drinking water. There are options out there for all budgets.
- Separate cutting boards for different foods
- High-quality food storage containers
-

Chapter 14: Post Transplant: Understanding Graft-versus-Host Disease

You build up to finding donor, the match and the preparation for the transplant . You have fought so hard to get here: the protocol, the conditioning, the transplant itself. Then the donor cells are in, and you wait to be told it is a success.....but this takes time.

If your child has received donor stem cells - an allogeneic transplant - you will hear the words, Graft-versus-Host Disease - abbreviated to GVHD. Your transplant team will explain it, you'll read about it in the information packsone more thing to watch for.

When donor stem cells are transplanted into your child, those new cells carry their own immune system, specifically a type of white blood cell called T-cells. These T-cells are meant to rebuild your child's immune system but sometimes they look at your child's organs and tissues and don't recognise them as home. The graft - the donor cells - sees your child's body, as something foreign, something to attack.

This is not something you face if your child received their own stem cells back (an autologous transplant) but for those of us on the allogeneic path, GVHD is a reality you need to understand.

Most cases are mild or moderate and they do resolve over time. Hold onto that. However it can be more severe and, in some cases, life-threatening, so you need to know what you are watching for.

There are two types. Acute GVHD usually appears

in the early weeks and months after transplant. It tends to affect the skin, the gastrointestinal tract, and the liver. Chronic GVHD can come later, sometimes months, sometimes years, and it casts a wider net. The skin, eyes, and mouth are most commonly affected, but it can also reach the nails, hair, joints, lungs, liver, muscles, and, in rare cases, the nervous system. Your child may develop one type, both, or neither. Sometimes both can present at the same time.

Treatment is in the main with steroids and immunosuppressant drugs during the first 100 days post transplant. Your transplant team will be monitoring closely. Blood work, skin checks, watching for changesand so will you.

The First 100 Days

Those first 100 days. I cannot stress this enough, this is when vigilance is at its highest. Not just from the medical team, but from you. You and your patient are the one who will notice a change in the skin before the next appointment. You are the one who will feel that something is not quite right, the way you learnt to feel their skin for fever back in those early days on the ward.

As a carer you need to really use all of your resources during this time and hold a very strong routine of hygiene, nutrition, and environmental wellbeing, for both yourself and your patient. Everything you have learnt in this book about creating healing spaces, about clean environments, about supporting the immune system through nutrition and complementary carethis is where it all comes together. This is possibly where it matters most.

Clean hands. Clean spaces. Clean food and the diffuser running. The same rituals, morning and night. Cleanliness became our routine — and post-transplant, it becomes your lifeline.

These 100 days will ask everything of you when you are exhausted physically, mentally and emotionally. Keep your personal care routine so you can be the best version of yourself.

Your transplant centre will have a specialist team to help you over this difficult period. Lean on them and ask every question. There is no such thing as a silly question when your child's immune system is being rebuilt from the ground up.

Further Resources

For really comprehensive details on GVHD and post-transplant care, these websites will support you:

www.bmtinfolnet.org — an invaluable resource for bone marrow transplant patients and their carers, with detailed guides on GVHD, recovery, and long-term follow-up.

www.bestpractice.bmj.com — for when you want to understand the clinical side in greater depth.

These resources go further than this book is designed to go. Once again I find myself just saying this is our lived experience, the things we did, the things I wish someone had told me.

The transplant is done. Now hold your routine, trust your instincts, lean on your team, and take it step by step.

Creating Healing Rituals at Home

Daily Sanctuary Practices:

- Morning aromatherapy routine
- Gentle movement or stretching
- Meditation or quiet reflection time
- Nutritious meal preparation rituals

Evening gratitude and relaxation practices

Weekly Deep Care:

- Epsom salt detox baths
- Carrier oil massage
- Deep cleaning and space clearing
- Meal preparation and planning

Checklist

Deep Clean & Declutter the Space:

- Think: minimal, breathable, easy to wipe, no dust traps.
- Remove plants (mould risk), rugs, curtains, extra fabric items
- Switch to blinds instead of curtains (easier to clean)
- Clear ornaments, books, clutter—dust-collectors
- Keep only what's essential, soothing, easy to wipe

Hygiene & Infection Control:

- No pets during neutropenia or high-risk periods
- No visitors during vulnerable phases (or only outdoor, masked, distanced)
- Open windows often for fresh air circulation
- Clean products and packaging before they enter (as we did during COVID)
- Wear masks indoors during high-risk days

PART V: MOVING FORWARD

Chapter 15: A New Kind of Strong

The Mental Battle:

“You never know how strong you are until being strong is your only choice.” — Bob Marley

There’s something you come to understand when you’re living through cancer with your child: no matter how many people are around you, no matter how many others are going through it too you are still on your own journey.

It’s human to look sideways. To ask, “What about that boy? That family? That case?” You want to know how someone else did it. What the outcome was. Whether their story might somehow mirror yours, and if so, whether it ended in hope. We all ask the doctors for survival rates. For statistics. For percentages. It’s one of the first things we search for online. We’re desperate to measure our fear against something. But those numbers, whilst real, don’t tell you the truth of your experience.

Because the truth is this, even two people with the same diagnosis, on the same protocol, in the same hospital, are living two completely different realities. That’s what no one tells you. It’s not just about how the body responds to treatment. It’s about how the mind

holds on. How the emotions hold up. How the spirit weathers the storm. And that part? That's entirely individual.

Cancer is physical, yes. But more than that, it is mental. It is emotional. It is psychological. It is spiritual. It's a daily mental battle for the patient and for the people who love them.

Some days, you're just trying to get through the next hour without collapsing under the weight of it. Some days, your mind is louder than the disease itself—what if, what now, what next? You're managing not just the physical side effects of treatment, but the emotional fallout. The fear, the constant worry, the isolation. The sheer exhaustion of pretending you're okay for everyone else when inside, you're breaking.

That's why you can't compare. That's why you have to stay focused on your own lane. Not just to protect your energy, but to survive it with any piece of yourself still intact.

For us, taking control of even the smallest things made a difference. Food, Sleep, Laughter, Energy, Music, Nature. Whatever kept us feeling human because mental strength isn't about pretending to be fine, it's about choosing, again and again, to keep going towards the Light.

So if you're in it right now, if you're walking through it, know this: your mind is your most powerful tool. Protect it, Feed it, Rest it. Let yourself cry, let yourself scream but don't give up and keep searching for the tools that can heal you and your family. Cancer is not just a physical battle... it's a mental one.

"Only in the darkness can you see the stars." —
Martin Luther King Jr.

“Out of difficulties grow miracles.” — Jean de La Bruyère

Before and After

The family that enters cancer treatment is not the same family that emerges. This isn't loss—it's evolution. You've been forged by fire, and while the process was brutal, the result is a family with:

- Deeper appreciation for ordinary moments
- Stronger advocacy skills for yourselves and others
- Enhanced empathy for suffering and struggle
- Unshakeable bonds forged through shared battle
- Practical resilience for handling future challenges
- Spiritual growth regardless of religious background

Integration Process

Recovery isn't just physical—it's psychological, emotional, and spiritual. Allow time for:

- Processing the trauma you've all experienced
- Grieving the losses alongside celebrating victories
- Rebuilding relationships affected by the crisis
- Discovering new family rhythms and traditions
- Honouring the journey while moving forward

Post-Treatment Challenges

Survivor's Guilt and Anxiety:

- Guilt about surviving when others do not
- Anxiety about recurrence and future health
- Difficulty trusting that you're truly "safe"

- Hyper vigilance about symptoms and changes
- Trouble enjoying normal life experiences

Family Readjustment:

- Siblings who felt neglected during treatment
- Marriages strained by prolonged stress
- Financial recovery from treatment costs
- Career and educational rebuilding

Social reintegration challenges

Identity Reconstruction:

- Moving beyond “cancer family” identity
- Rediscovering interests and goals outside medical care
- Balancing continued medical follow-up with normal life
- Deciding how much to share about your experience
- Finding purpose in your survival story

Sharing Your Experience:

- Mentoring newly diagnosed families
- Volunteering with cancer organisations
- Sharing practical tips and emotional support
- Advocating for better policies and support systems
- Contributing to research and awareness efforts

Living Your Values:

- Prioritising what truly matters
- Maintaining perspective on daily challenges
- Demonstrating resilience to your children
- Contributing to your community’s wellbeing
- Creating meaning from your experience.

The Practice of Gratitude

A daily practice of gratitude acknowledges all the people and experiences that have sustained you and your loved ones. I know that whilst going through a cancer diagnosis, protocol and the “fall-out” of cancer may seem contrary to gratitude. I am certainly not one who ever says they are grateful for what cancer has done to our lives, not at all. However I am saying that when you are digging deep to sustain your mental and physical health, this practice is just one that has been shown to help your overall health and well being.

Research shows that practicing gratitude — 15 minutes a day, five days a week — for at least six weeks can enhance mental wellness and possibly promote a lasting change in perspective. Gratitude and its mental health benefits can also positively affect your physical health.

Like most health practices, you get the biggest benefits from having gratitude when it becomes habitual and part of your thought process. You can allot specific times in your daily or nighttime routines or just find moments as the day unfolds.

Taking time to be thankful may:

- **Reduce depression:** A review of 70 studies that include responses from more than 26,000 people found an association between higher levels of gratitude and lower levels of depression. But more research needs to be done to understand the association.
- **Lessen anxiety:** Anxiety often involves worrying and negative thinking — typically about things that happened in the past or may occur in the future. Gratitude can be a coping tool for anxiety.

Regularly practicing gratitude combats negative thinking patterns by keeping thoughts focused on the present. If you find yourself focusing on negative thoughts about the past or future, challenge yourself to find something you are grateful for now. It will break the negative thought process and return you to the present.

- **Support heart health:** Several studies have shown that a grateful mindset positively affects biomarkers associated with the risk for heart disease. A 2021 review of research also finds that keeping a gratitude journal can cause a significant drop in diastolic blood pressure — the force your heart exerts between beats. Having grateful thoughts, even if you don't write them down, also helps your heart by slowing and regulating your breathing to synchronise with your heartbeat.
- **Relieve stress:** Stress triggers a fight-or-flight response in your nervous system — your heart beats faster, muscles contract and adrenaline pumps. But gratitude can help calm the nervous system. Taking a moment to be thankful causes physiological changes in your body that initiate the parasympathetic nervous system — the part of your nervous system that helps you rest and digest. Gratitude and the response it causes help bring down your blood pressure, heart rate and breathing to help with overall relaxation.

Tips for practicing gratitude

Many people think of gratitude as a trait. But if you practice it, focusing on the positive things in life can become a habit and eventually becomes natural to you.

The best way to form a mindset of gratitude is to

slip it in throughout the day. You can incorporate more gratitude in your life by:

- **Writing it down:** Take time either at night or in the morning to write down something that went well. Dedicate a notebook or journal to gratitude so you can reflect and remind yourself of those moments. You can use the notes pages in this book at the end of each chapter as reasons to be thankful appear.
- **Hitting pause:** Many of us reflexively say, “thanks” often. Next time you hear yourself say it, stop and pinpoint precisely what you are thankful for.
- **Redirecting your thoughts:** You may feel negative or frustrated during the day. When that happens, step back and shift your focus to a positive aspect of the situation. My example here is even when in the most terrible hospital situations I could be grateful for the nurse or doctor that was trying to support us. I was forever grateful for having a son who so nobly took treatment with complaining or asking “why me?”
- **Sharing your gratitude:** Send a quick note telling someone why you are thankful for them or encourage your family to share something they’re grateful for each night at dinner.

The Gratitude Practice

Our donors - My daily devotion to our transplant donor:

To all those who donate plasma

To all those who donate blood

To all those who work for the Anthony Nolan Trust and to whom 10% of the earnings of this book will go

To all the Nurses and Doctors In Spain and the UK

To all our Friends who were there through it all or even part of the journey

Angels who appeared:

Cristina, Alberto Sr and Alberto. Maria an unknown mother who donated a new phone that helped Ramsey. All the school friends and teachers who fund raised for us, to the "Beauty Boys" who held us on our pilgrimage up La Concha to raise money for self employed parents who had no financial support when they cannot work - as is the case in Spain.

To all the school teachers from Aloha College, Marbella and at Grey Court School, London who enabled Ramsey to be able to study in hospital and at home for his school exams for 4 years.

To family who could stand with us, my mother in law, my sisters and aunt.

To all strangers who could stand with us, who are now our unconditional friends for life.

My husband, for being my rock when our relationship and family was crumbling beyond recognition.

Lastly but probably the most important people of all, my sons, Ramsey and Max, my greatest inspirations, my greatest teachers.

Chapter 16: Resources and Support

Medical and Treatment Resources

Major Paediatric Cancer Organisations:

United Kingdom:

- Children's Cancer and Leukaemia Group (UK Based): www.cclg.org.uk Dr. Boo Messahel has compiled and edited a very comprehensive brochure you can download to help both parents and children with lots of advice and information.
- www.Cancer.gov have published a great information site and brochure for all age groups
- The Macmillan Teenage Cancer Unit - www.macmillan.org.uk/
- Cancer Research UK - www.cancerresearchuk.org
- Comprehensive parent and child support materials
- Macmillan Cancer Support: www.macmillan.org.uk

Teenage Cancer Trust programs and resources

- The Anthony Nolan Trust: www.anthonynolan.org
- Bone marrow and stem cell transplant support
- Young Lives v Cancer www.younglivesvscancer.org.uk (formerly known as Clic Sargent) charity that supports in so many ways and has workers who can speak to you face to face to help with your family situation

International:

- Childhood Cancer International:
www.childhoodcancerinternational.org
- International Society of Paediatric Oncology:
www.siop-online.org

United States:

- Children's Oncology Group (COG):
www.childrensoncologygroup.org
- Clinical trials information and research updates
- St. Jude Children's Research Hospital:
www.stjude.org
- Treatment information and family resources
- American Childhood Cancer Organization:
www.acco.org
- Children's Hospital of Philadelphia (CHOP) -
www.chop.edu

Family support and advocacy resources

There will be groups on social media that at times may be of help and at other times you may want to distance from. However the groups can be a real support and also you can ask questions you may not dare voice out loud to others.

There are stories of hope on there too. Remember that hope is what you have to surround yourself in. Believe in Miracles for that is what you are. That is what each and every one of us is and we have to believe that just for us to be here today, generations of fighters have got us here. Keep hope, keep fighting and keep believing in Miracles.

Contact details of some wonderful people who helped us

- Francesca Hillman (TCM doctor) who works internationally - francescahillman@gmail.com
- Hanne at The Real CBD: www.therealcbd.com
Use discount code KAY25 and get 25% off all products
- Joanna Sha who works internationally as a healer and teacher on Energy healing: www.joannasha.com
- Dehydrated Bone Broth: www.drgusnutrition.co.uk

Financial Assistance Programs

- Government and Charity Support:
- Hospital financial counsellors and social workers
- Government assistance programs (varies by location)
- Religious and community organisation support
- Local cancer centre-specific assistance programs

United Kingdom:

- Macmillan Cancer Support: Financial guidance and grants - www.macmillan.org.uk/
- Young Lives vs. Cancer (formerly CLIC Sargent): Family support and financial assistance - www.younglivesvscancer.org.uk
- The Family Fund: UK's largest charity providing grants for low-income families raising children or young people who are disabled or seriously ill - www.familyfund.org.uk
- Make-A-Wish Foundation: Wish fulfilment for qualifying children - www.make-a-wish.org.uk

- Ronald McDonald House Charities: Housing near treatment centres - www.rmhc.org.uk/our-houses

United States:

- National Foundation for Cancer Research: Grant programs for families - www.nfcr.org/
- The Leukaemia & Lymphoma Society: Financial assistance and co-pay programs - www.lls.org/support-resources/financial-support/co-pay-assistance-program
- Ronald McDonald House Charities: Housing near treatment centers - www.rmhc.org/our-core-programs/ronald-mcdonald-family-room-programs
- Make-A-Wish Foundation: Wish fulfilment for qualifying children - www.wish.org/home

General Financial Resources:

- Hospital financial counsellors and social workers
- Government assistance programs (varies by location)
- Religious and community organisation support
- Crowdfunding platforms (GoFundMe, YouCaring)
- Local cancer centre-specific assistance programs
- Mental Health and Counselling Resources
- Specialised Cancer Counselling:
- Cancer Support Community: www.cancersupportcommunity.org
- Psycho-Oncology Society: Professional therapist directory
- Association of Paediatric Haematology/Oncology Nurses: Family support resources

Online Support Communities:

- CaringBridge: Patient update and support web-

- sites - www.caringbridge.org
- www.cancer.net: Patient and family education resources
 - Children's Hospital of Philadelphia (CHOP): Educational materials and support - www.chop.edu

Mental Health Resources

Crisis Support:

- National Suicide Prevention Lifeline: 988 (US)
- Crisis Text Line: Text HOME to 741741
- Samaritans: 116 123 (UK)

QUICK REFERENCE GUIDES

Emergency Hospital Bag Checklist

Immediate Grab Items:

- Insurance cards and ID
- Current medication list
- Emergency contact information
- Phone chargers
- Comfort items (blanket, pillow)
- Change of clothes for patient and caregiver
- Basic toiletries
- Cash for parking
- Snacks and water bottles

For the Carer - The Strength Behind the Strength

Keep your space organised and always have a journal and pen to hand. Day and night write down anything you observe that can be of help to the other carers and the health providers. A routine in a hospital space will give a rhythm and sense of control to your day.

Nourish yourself with good snacks and healing drinks. Keep on top of health supplements that your health care provider or a nutritionist recommends. Caring for your body will be invaluable as your mind and body are tested like never before.

Practice grounding: a 5-minute breather, a hot drink, a stretch routine. Do “your thing” whether that is strumming the guitar, rolling out your yoga mat, getting out your knitting needles or going outside for a scream and cry.

Know you don't have to be perfect. Just be present. This is why I have included the various breathing exercises throughout this book. Keep coming back to the breath and be present in the best way you can.

This checklist can live on the fridge, the wall, or in a journal beside the bed, a reminder of how healing is built in every small choice, every wiped surface, every warm blanket.

You too one day will be able to give this information to another mother or parent or carer.

Final Words: A Message for the Journey Ahead

Nine years after diagnosis, I can tell you with certainty: you are stronger than you know. The path ahead is difficult, but it's not impossible. You will find reserves of strength, courage, and love that you didn't know existed.

This guide represents thousands of hours of lived experience, research, advocacy, and learning. But your journey will be unique. Use what serves you, adapt what needs changing, and trust your instincts about what your child needs.

Remember:

- You are your child's best advocate—trust your observations and intuition
- Healing happens in many ways—support the body, mind, and spirit
- Community sustains you—accept help and offer support when you can
- Small steps matter—progress happens gradually, not all at once
- Hope is a choice—choose it daily, even in dark moments
- For the difficult days: Step by step, paso a paso.

Breathe in hope, breathe out fear. You are not walking this path alone. Thousands of families have walked before you, thousands walk beside you now, and your experience will light the way for families yet to come.

Hope is everything. It is the light at the end of the tunnel when you see no light. You just have to believe,

go step by step and one day you will again live in the light.

“Hope is being able to see that there is light despite all of the darkness.” — Desmond Tutu

In memory of all the brave children who didn't make it home, and in celebration of all those who did. In gratitude to the medical teams who dedicate their lives to fighting childhood cancer, and to the families who never give up hope.

About This Guide: A portion of proceeds from this guide supports The Anthony Nolan Trust and other organisations dedicated to childhood cancer research and family support.

Disclaimer: This guide represents personal experience and research, not medical advice. Always consult with your medical team before implementing any strategies discussed here. Every child's situation is unique, and treatment decisions should always be made in consultation with qualified medical professionals.

Thank you for reading.

I am looking forward to reading your feedback.

You can leave a review here:

www.amazon.co.uk/dp/B0GSX46FMP

If you can purchase a copy, please know that a portion of every print copy sold goes to The Anthony Nolan Trust and Young Lives vs Cancer.

With love,

Kay