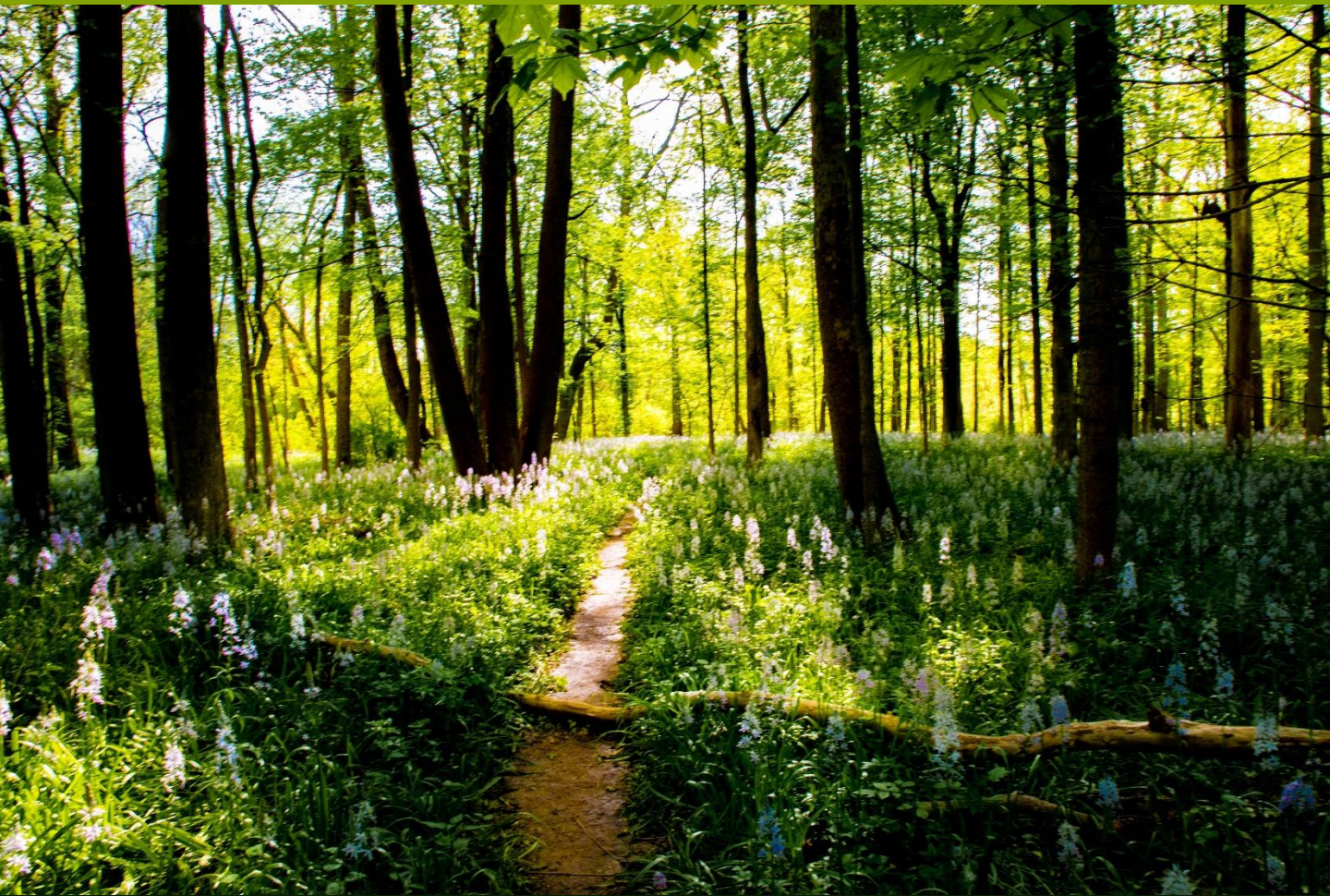


Finding A Way



Introduction

DISCLAIMER

The aim of the “Finding a Way” video series is to provide parents and caregivers of children with serious brain disorders or other serious illnesses with guidance on navigating and coping with the stressors they may experience in their caregiver role.

The advice in the “Finding a Way” video series is **general advice only** and does not take into account individual medical, psychological or physical conditions or needs. **It is not intended to be and should not be relied upon as a substitute for specific medical or mental health advice.**

If you have questions or concerns about any medical, psychological or physical matter, you should consult your doctor or other professional healthcare provider without delay.

Sydney Children’s Hospitals Network does not accept any liability for any direct or indirect loss, expense, injury or damage whatsoever incurred by use of or reliance on the advice provided in the “Finding a Way” video series.

If you or anyone you know needs help, call:

Lifeline on 13 11 14

Kids Helpline on 1800 55 1800

**If in immediate danger, call 000 or go to your nearest
Emergency Department**



Finding A Way

Introduction

Welcome to 'Finding a Way'

These six brief talks are designed for parents of children with severe epilepsy that persists over a long time. In one sense they may be of help for any parent who has a seriously ill child. But they are especially prepared with parents of young children with very serious brain disorders in mind.

Where we are in the journey with our child and family will make a difference to how much we can take in, how much we want to focus on the positives that will help, or the struggles that we need words to express.

The Finding A Way series aims to go a small way to bridge the gap between the language of medical science and the language of our personal experience as parents.

The talks reflect different voices, and different stages in the journey, shared by families including the joys and

heartache experienced when caring for children with severe epilepsy.

We hope that you will find a way through the initial feelings of shock, of isolation, and uncertainty, to a place of some peace and joy with your child, even if there are times of sadness, in living the journey with your child and family and with other families on a similar journey.

Professor Nunn, a child and family psychiatrist who presents the Finding A Way series, is one of many people who have worked with families and children with serious brain disorders. He, like most people in the caring professions, has had children and family members who have been seriously ill.

No two illnesses are the same and no two families are the same. Nevertheless, he hopes that you find the suggestions, some seemingly simple, helpful.

Finding A Way



One

Shock, Confusion and Uncertainty

“A seizure in a very tiny newborn baby is a little tap of the arm, or a tap of the foot, it’s just a minute little movement. So, for such a minute little movement to have such a big impact and knowing it would limit her life and that she’d never walk or talk, the degree in which that would affect her”



“It was like I was dreaming – I couldn’t react. I was just there, sitting there on that chair. I couldn’t talk. There were many, many thoughts in my head, and yeah... I was without words. Part of me didn’t want to believe what I was listening to”

Finding A Way

Shock, Confusion and Uncertainty

There is so much joy in preparing for a child coming into a family. Of course, there are fears but mostly things turn out OK, don't they...? We live in a modern advanced economy with the best medical care and our friend's children have been OK.

We have to put our fears to one side, to the back of our minds. Otherwise, we would never do anything and miss out on what everyone else experiences.

Except we did.... miss out on what everyone else experiences. And our fears came from where we thought they would stay, in the back of our minds.

They are no longer in the back of our minds but filling our whole headspace. We are left with a total inability to make sense of what has happened to our child and our lives.

Our child was so small and so helpless. We felt so small and so helpless to face what we couldn't see – our child's brain – and to face what we could see, the seizures, the crying and the unknowing stares.

It was the uncertainty and, in a way, it still is. The uncertainty with a profoundly unwell child, with a brain disorder that is life limiting and does not have a well-known name, a well-known story of how it will play out, and does not have a well-known treatment.

The long journey to try and find a name for what we cannot understand, a diagnosis, a way of talking about it with our family, with our friends and with our work mates. Why does it have to be so hard, involve so many names and so little real change in what we do about it? The name means an answer doesn't it...? A treatment...? A group of people with the same problem ... the same sort of battle?



Finding A Way

Shock, Confusion and Uncertainty

Sometimes, none of these things quite work out as clearly, neatly and helpfully as we might imagine, or wish for.

Sometimes the hardest part of explaining what is going on with our child is trying to explain it to ourselves.

In this series I will not be giving you an explanation of what is happening in your child. Each child's condition is so very different. Every parent is also different, but there are some things that parents of seriously ill children have in common. I will be concentrating on what will be happening, or has happened, to you and in you.

Some things we do as parents can make life just a little bit more manageable and some things will make it almost impossibly hard.

There are no easy answers, but there are some basic rules that we can follow.

They are not high-tech rules. There are no complicated medical terms. You can be the smartest person in the world, or the person who always took longer than everyone else to 'get' what was going on.

In the end, when it comes to our own children, it is not about intellect, or strength of character, or 'who you know'. We are all faced with our limitations, the limitations of life itself and the limits our little ones and their bodies have.

I want to suggest just three simple rules for you to get through this time.

Finding A Way

Shock, Confusion and Uncertainty

1

Give time for the bad news to sink in – don't rush to understand everything straight away.

There is a feeling that we must get on top of everything all at once.

We may never have encountered something that we cannot get round, get over, or push through. Or we may have, and we may feel this will be another 'impossible'.

In either case, don't rush to understand.

Give yourself time to let the news sink in and time to slowly assemble the pieces of what this means for you and for the other members of your family.

Give yourself time to work out what it means for your little one – what will be their battle and what will be yours.

Their battle and our battle as parents are quite different.

It takes time to realize that difference.

Finding A Way

Shock, Confusion and Uncertainty

2

Listen to the right people

Even when people mean well, they may have very little understanding of what they are talking about. At first, answers given by doctors, even the best doctors, don't seem 'right'. They seem incomplete, unsatisfying and annoying. The doctors seem to hesitate, become vague and reluctant to commit themselves as to what will happen in the long term. They seem unduly pessimistic and make us think of movies where the doctors got it all wrong.

Sometimes, we doctors do get it wrong, or we just handle it wrongly. We know that what we know is limited, our predictions sometimes turn out to be wrong and our treatments fall way short of what is needed for a child to have a normal life. But there are doctors who have dealt with hundreds, sometimes thousands of children with the cluster of brain illnesses our child has. Paediatric neurologists, and their multidisciplinary teams of nurses, psychologists, social workers, occupational therapists and many others, have deep and broad training and experience in what can go wrong with children's brains and why and what can be done, and not done.

We, as parents, slowly work out who to listen to; who is most reliable, trustworthy and who does not set us up for disappointment; who gives us what real hope they can, at each step of the way.

Finding A Way

Shock, Confusion and Uncertainty

3

Try to work out a plan for TODAY

The past is too hard to make sense of all at once. You will only have the strength and understanding for TODAY and sometimes just for the next few hours.

If we rush to face our children's future, we will be swamped with our helplessness, our powerlessness, and our lack of certainty about every possibility. The future is too heavy to carry all at once.

If we try to put together all the pieces of the past – how did we get here, why has this happened, who is at fault, what did I do wrong – we will find ourselves blaming others, blaming ourselves, somehow ashamed and guilty and yet not knowing why.

The past must be taken slowly. 'Why' questions are very difficult to answer. Sometimes it is not about blame but about a sad fact of life, a sad fact of our lives.

Taken one day at a time and, sometimes, just a morning, or an afternoon, or a brief exhausted evening at a time, is the best we can do.

Finding A Way

Shock, Confusion and Uncertainty

Summary

Let the news sink in

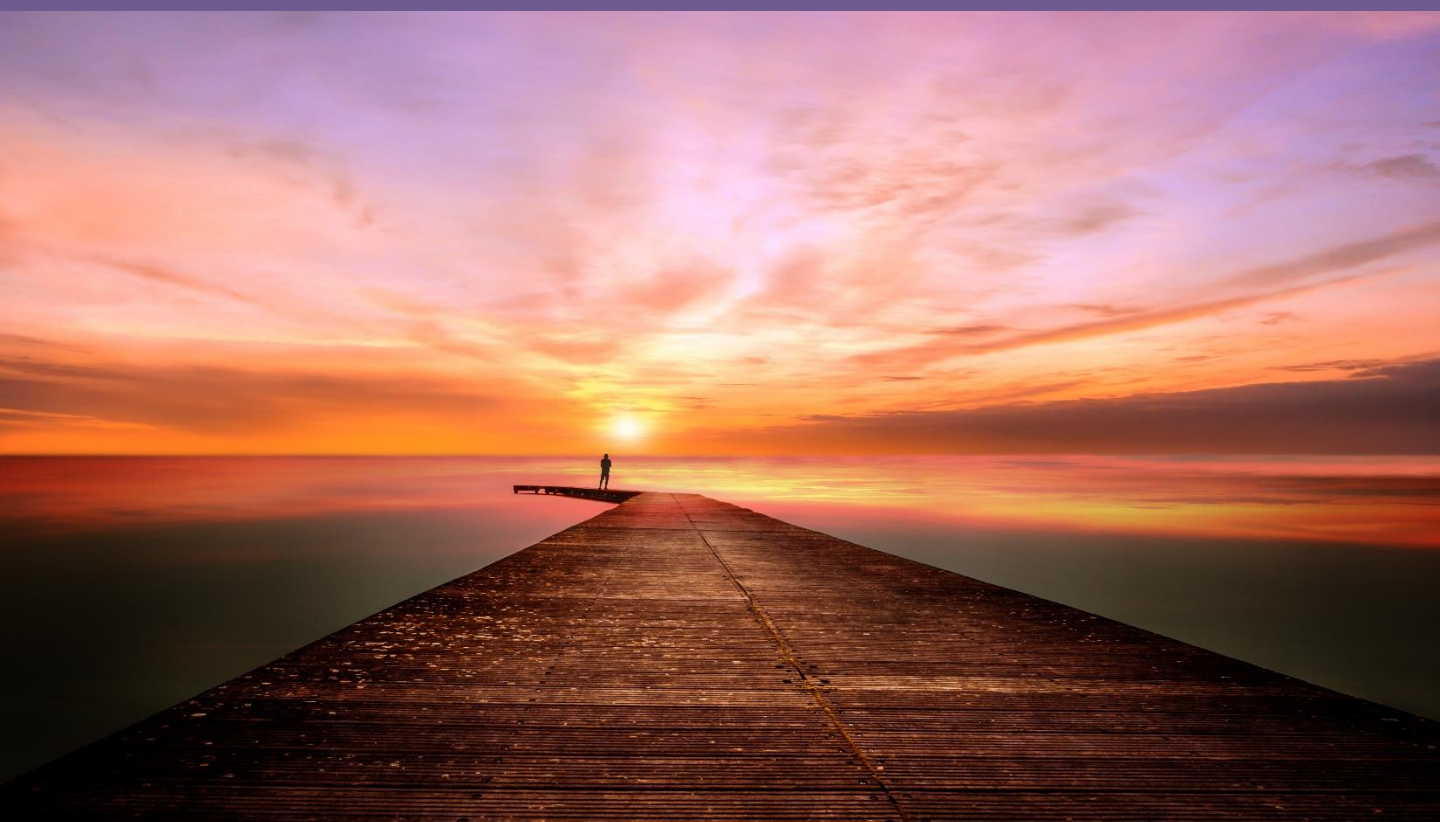


Listen to the right people



Live one day at a time

Finding A Way



Two

No one understands – I'm on my own

“As a parent of a young child with a diagnosis, you feel really alone. Your child is needing so much medical care that you don’t necessarily have time for friends. You don’t necessarily know anybody else that’s on your journey.”



“It’s really scary and, it just makes you feel really isolated. You’re not getting out to meet other people. You don’t feel like you can manage getting out of the house, plus managing your child...making sure that they’re going to be okay.”



Finding A Way

No one understands – I'm on my own

Our pain feels worse than other people's pain. Our child's pain feels worse than any pain that we might see in another person. It is as if our child is physically part of us. Pain is a very personal thing. When pain is 'my pain' or 'our pain' it is very different to other people's pain.

The difficulty of understanding other people's pain is something that is part of being human. When others do not understand, and we cannot understand why they do not understand, we may feel that no-one understands. We come to believe that we are struggling on our own, that we are alone, even when others are about us.

It is hard for us to make others understand, to feel that they 'get it' and to share our situation. It is so hard to feel supported, when each person in the family has different needs, is in a different stage of dealing with what is happening and has different styles of coping.

The pacing of pain is so different even in the same family. The responses to pain are so different in each person. Each person may feel that others don't understand, even when they seemed to be going through the same nightmare.

At first it does seem that that no one understands. But then we realize that we often do not understand the suffering of others. We slowly accept that others can only understand our pain in part, just as we can only understand their pain in part.

We all have trouble understanding the suffering of others. We all see the world through our own suffering. Would we have understood what someone in our position was going through if this had never happened to us? What do we do about this feeling of being alone and misunderstood?

I want to suggest three simple rules to get through this time.



Finding A Way

No one understands – I'm on my own

1

Be understanding about other people not understanding

We all have difficulty understanding other people's struggles, diseases and life situations. Everyone does not have to understand and everyone does not have to understand everything about our problem.

What we do need is to have enough people understand to help us through and those people to understand enough to be helpful.

Some people can be really helpful without understanding at all.

Some people who understand may not always be helpful.



Finding A Way

No one understands – I'm on my own

2

The help won't be perfect... but accept what you can

When people try to help, but don't really get it, try to accept the bits that do work and ignore, or overlook, the rest.

When people offer us comfort, accept their intention, even if they don't say it in just the right way, with the right words, or they have the wrong facts.



Finding A Way

No one understands – I'm on my own

3

Allow other members of the family to express their struggles in their own way

Don't expect other members of the family to cope your way.

If their way means you are 'left to do it all' then start with understanding why they might be doing it their way and then let them know what you need them to do, practically.

Sometimes, if we criticize the help too much, people don't want to help us.

Finding A Way



No one understands – I'm on my own

Summary

Here's the summary and I hope it helps enough for you to feel that you are not alone, there are people who understand and there are lots of different ways of coping with our struggles, even in the same family.

Understand people NOT understanding



Recognise the help won't be perfect



Allow the people around us to deal with their struggles in their own way and in their own time

Finding A Way



Three

When the struggle feels too much

“The worry of what it could be and the worry that you're not doing - like what if it is this thing and we're not doing enough to help him in the meantime? ...So yeah, the worry about not doing enough, doing too much, all that sort of stuff.”



“Putting a name to something, I suppose is nice. But at the end of the day it's how that's going to affect her life. Because we can deal with what comes our way in relation to her, but emotionally I don't know how I'd deal with knowing that it was going to cause her to have an early death. So I think that that was my biggest - that's always been my biggest concern.”



Finding A Way

When the struggle feels too much

There are times when we cannot 'get our head around' what is happening to us and to our child. It is difficult to hear what is said, difficult to think and even difficult to know what we are feeling. We are overwhelmed. We are overwhelmed by the medical world we are drawn into by our child's illness. New words. New people. New decisions we thought we would never have to make.

We do not feel up to what is being required of us. It is difficult to go onwards because we don't know where 'onwards' is, which way to go. We try to ask for help, although we are often not quite sure what to ask for and the help doesn't seem to help enough. We try with all our effort, our understanding and all our skills and we still find that there are 'storms that can't be weathered' and 'dreams that cannot be'.

We find ourselves caught in a nightmare from which we cannot escape.

At the same time, people are being courteous, professional and friendly. We find ourselves responding best we can on the outside and falling apart on the inside.

They are trying to be so helpful and we feel so unhelped. We may even feel ashamed that we are so inadequate to the task of helping our child. Part of us may want to withdraw from everyone and everything, or to rage against the world for being so unyielding in providing what we need.

Hard to think; hard to feel; hard to act. Sleep can be broken. Food tasteless. The world hurtling on around us as if the huge events happening to us have no meaning or the huge events happening to others have no meaning to us.

Three simple rules will help us get through this time.



Finding A Way

When the struggle feels too much

1

**Make big unmanageable problems
into smaller manageable ones**

Starting with large problems and breaking them up into smaller ones, doing what is easier to do first and tackling harder ones as we are able.

Spreading problems out over longer time frames so that everything is not a crisis.

It is LONG HAUL coping that matters not creating crises 'to make things happen'.



Finding A Way

When the struggle feels too much

2

Accept what is unchangeable

Accept what is unchangeable rather than putting large amounts of futile effort into modifying what cannot be modified.

This is the hardest rule even though it is simple.

It takes time to work out what you can change and what you cannot. Sometimes we may find we are uncertain about this for quite a while. But when we do work it out, it can save a lot of pointless effort and target our emotional resources to what is possible.

We stop trying to change the unchangeables and controlling the uncontrollables.



Finding A Way

When the struggle feels too much

3

**Separate what the struggle is for our child
from what the struggle is for us**

Mostly our struggle as parents is relieving the struggle of our child.

Actually, our struggle as a parent is much more than that of our child because so many memory systems don't work in our child but do work in us.

Seizures happening in our child will distress us but our child is unaware of them. Heart rending screams and movements are interpreted as pain by us because they are painful to watch and they look like a child in pain.

We are often traumatized by things of which the child may have no memory.

It is not always so, but it is often so.

As parents we can be sometimes be weighed down by our child's future while they may be unaware of it.



Finding A Way

When the struggle feels too much

Summary

Move the mountain one shovel full at a time



Change the changeables

Accept the unchangeables



Don't confuse our struggle with our child's struggle





Finding A Way

When the struggle feels too much

Notes

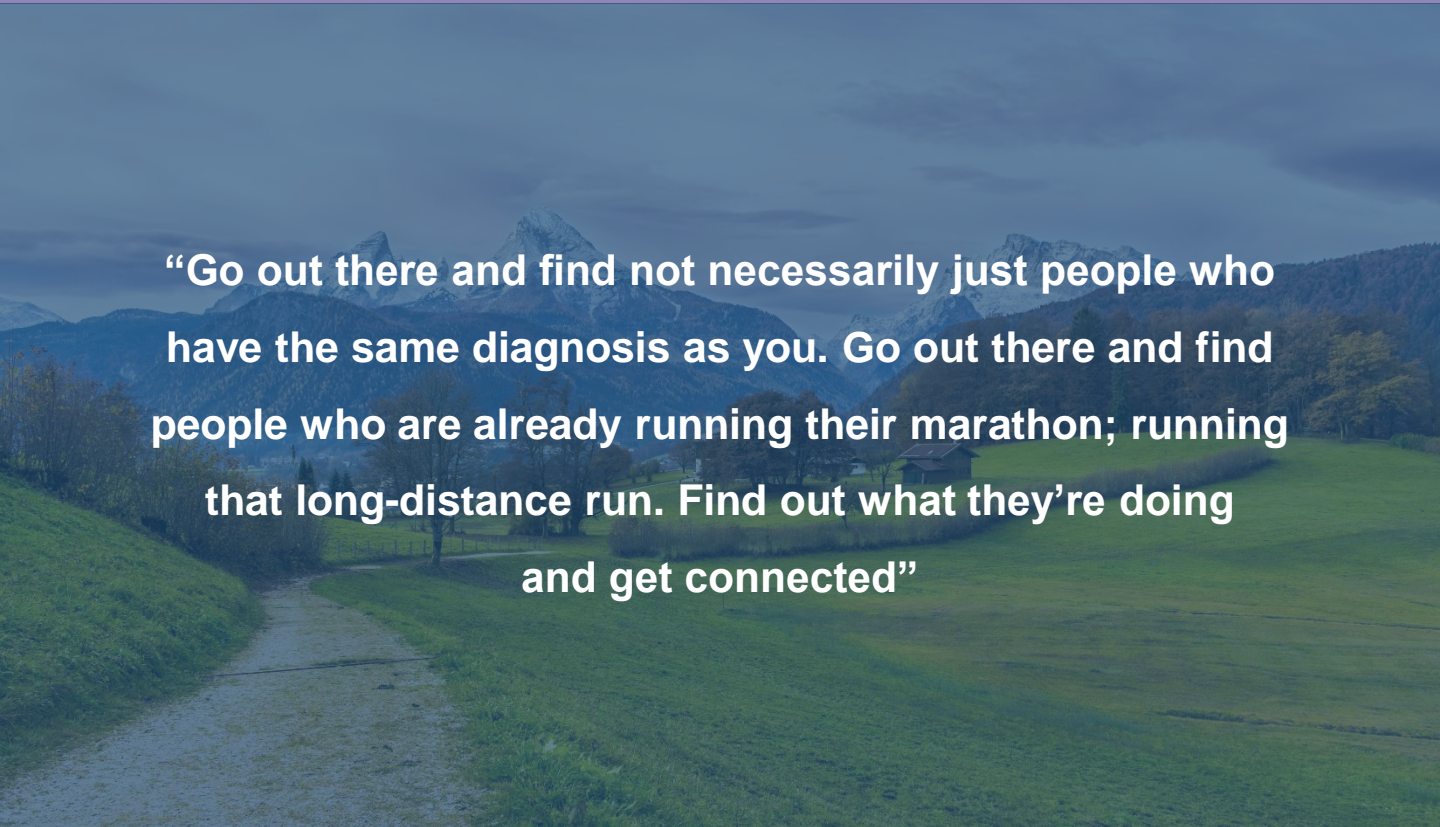
Finding A Way



Four

**Putting the pieces together and
going forward**

“Where people are in a journey is very specific to what they need, and I guess my advice is to get the right help, make sure the support is specific to where you’re at and what your child’s condition is.”



“Go out there and find not necessarily just people who have the same diagnosis as you. Go out there and find people who are already running their marathon; running that long-distance run. Find out what they’re doing and get connected”

“It’s getting to know other parents in that early diagnosis period, being able to touch base with other people. Even if their kids have got different diagnoses to yours, it’s knowing that someone else is there too, and this is what I’m trying...”



Finding A Way

Putting the pieces together and going forward

Well, we all thought getting a diagnosis is what matters and it certainly stops us from getting wrong diagnoses and using wrong treatments.

Slowly, we realize that it is not just about getting a diagnosis, having a name for our child's condition, but about appreciating what it means for our child and for us and what we can actually do to help.

The search for THE diagnosis is important but it may not change my child's condition.

The search for THE world expert may be reassuring, but it may not change the treatment.

The search for THE support group with exactly the correct title may mean we at last feel no longer alone, but, even then, every child is different.

Some people with children with very different conditions will have more to teach us about coping with our situation than a parent who might have a child with the same genetic mutation, or molecular channel defect.

And while we have found a diagnosis, have we left the rest of our family behind? If we are 'the authority' in the family about this illness, does this mean that what everyone else feels and thinks doesn't matter?

Each brother or sister, and our partner, needs to have some understanding that will grow over time. They need to understand, as we do, without all the medical 'bells and whistles'... without all the medical terminology.



Finding A Way

Putting the pieces together and going forward

The more we can explain in non-medical language, the more they will understand and the more we really understand as a parent... as a family.

Each person needs a role to play without being unnecessarily overwhelmed. Our role as parents is to explain and to 'help our families help', not to swamp them with our feelings of being swamped.

If we are swamped, we may need to get our support away from the family with social workers, psychologists and others who understand these illnesses and the toll they take.

Much of what gets us and our family through is not technical but feelings and relationships.

Listening to experts doesn't solve everything but does help us to know what we are dealing with.

Listening to those who have come through difficult times doesn't stop us struggling but it does remind us we are not alone.

Listening for solutions instead of looking for who to blame saves us from bitterness and the rest of our family resenting our unwell child.

Three simple rules help us to get through this time.



Finding A Way

Putting the pieces together and going forward

1

**Make the search about finding a way to live as a family,
not just about curing this illness**

Some of the best minds in the world are working on these problems.

But we will have only one life and our children will have only one life. Giving them the best life may be much more important than a diagnosis for some children.

A cure is often not possible but comfort and caring for each other are always possible – for all the family.



Finding A Way

Putting the pieces together and going forward

2

Let everyone in the family find a role to play in caring, suitable to their skills and capacities

The other children need to have positive things to do as well as being given permission to get on with their lives.

Less capable partners need to know their less perfect care is better than no care at all instead of being side-lined.

Keeping the normal aspects of family life going can be critical.



Finding A Way

Putting the pieces together and going forward

3

Learn about the disease from experts and find out from those with other conditions what they have found helpful

We don't have to have had the worst, the most distressing or the most unimaginable disease with our child. What we have to deal with is already bad enough and what others have to deal with is often also bad.

Cut some slack to those people without our problems. It is not their fault that our life has been hard. We can all be just a little more aware that almost every family is touched by their own sadness.

Some of those who have never been touched are not always happy. Life can be a hard business for all sorts of reasons but with humour, imagination and friendship, and an awareness of the struggles of others, we can enjoy a more real and meaningful life than we might otherwise have had.



Finding A Way

Putting the pieces together and going forward

Summary

Make the struggle about family not about illness



Everyone in the family needs to feel they have a role but it needs to be manageable



Listen to the experts and listen to people with different struggles to our own



Finding A Way

Putting the pieces together and going forward

Notes

Finding A Way



Five

Finding a strange sort of strength together in the
midst of grieving

“It was full-on but we got through it... you learn to deal with it, you know what I mean? So, it was sad to start off with, but then you're like, alright, we'll keep trying, you know?... I think we're pretty good at adapting to situations and accepting our new reality”

“I always tell people, you don't realise how someone so little can teach you so much. So, the fact that he keeps fighting, you know, that kind of helps us to keep battling away.”

“I've actually got more positive over the years rather than less positive because she's making progress, and her initial prognosis was she wouldn't walk, she wouldn't talk. So I can see her making progress.”

Finding A Way

Finding a strange sort of strength together in the midst of grieving

There are losses in every family, griefs to be born and sorrows to be endured. The sorrows may be for the life hoped for that now cannot be lived as we had imagined - we are in sorrow for what our child will not have and will not be - the griefs as the world of illness and disease, life and death come to our home.

The losses of ordinary things; time to oneself, time for the trivial and time to play with each other as a family – these pass by almost without us noticing. The strange sense of our frailty, combines with getting through things we would never have believed ourselves able to do. The pain of grief, fragility of grief, the privacy of grief, are all so very real.

It seems hard to believe that there are deep times of solace and relief, deep moments of shared sadness and a quietly and slowly growing strength, the sort of strength that matters.

It is not public or showy, but it is shared among family and friends and sometimes has very few words and a can't-be-spoken quality.

It may not be what you have come to believe from others, or the media, people should do when sad, when grieving...

...Simple things like a small but tasty meal with friends, a good night's rest, a long unhurried walk and watching a favourite movie that is comforting, get us through some of the toughest times. Laughing about the craziness of life; being playful when we are sad and enjoying precious moments with our children, give us renewed strength and nourishment to face the impossible for another day.

Three simple rules may help us get through this time a little more easily.



Finding A Way

Finding a strange sort of strength together in the
midst of grieving

1

**Do what helps each other as a family,
not what we think others expect of us**

Others may not expect the way we manage as a family.
Even if they do, they must share some of the disappointments about our
very abnormal, normal lives.

Family and friends will come to understand over the first few years that
we are doing the impossible and cannot meet **our own expectations**,
let alone theirs. But don't grow impatient waiting for them to understand.

Focus on understanding each other within your immediate family and
accept that **some people will just not be able - ever - to 'take it in'**.

Others we know will surprise us and they are gold.



Finding A Way

Finding a strange sort of strength together in the
midst of grieving

2

Be gentle with our own bodies, our own minds
and our own feelings – they have limits

Our feelings can be stretched **past our own imaginings**.

Our minds – everyone's minds – are not adequate to the task of **caring for a child who never will be fully well** and whose life will never reach a 'prime of life'.

Our need for good sleep, good food and some physical outlet seem so unimportant at first and we couldn't take them if we had the opportunity.

But surviving the long haul, remaining **able to give**, being **bearable to live with** and having **a good life, despite our struggle**, requires us to take some time to look after ourselves.



Finding A Way

Finding a strange sort of strength together in the
midst of grieving

3

Don't be afraid of being weak, silly,
playful, tearful and laughing

There is no greater protection against the corrosive effect of grief than
returning to **the playfulness of our childhood.**

Playing with our children, ill or not ill, with our partner and with
our child who may not understand anything more than the pleasure of a
happy parent, helps us to grieve and find strength.

It is a funny sort of grief and a frail-feeling strength.

Finding A Way

**Finding a strange sort of strength together in the
midst of grieving**

Summary

**Do what helps each other as a family,
not what we think others expect of us**



**Be gentle with ourselves
– we have limits**



Don't be afraid of being playful and tearful



Finding A Way

**Finding a strange sort of strength together in the
midst of grieving**

Notes

Finding A Way



Six

The sort of hope that gets us through

“It's not so black and white. I mean of course it's very overwhelming in the beginning and there's a lot of challenge and there's a lot of uncertainty, and you find yourself being the hamster on the wheel trying to understand all the information and put all your services in place, but at the same time you've still got this hope that runs through everything that you do. You've still got this joy of having this child that's also more than their medical condition”



“I guess we've also reframed the whole thing in our minds; just growing a huge sense of appreciation for our child and for everything we've got. Not discounting all of the tremendous challenges, but I think that's kept us really positive and centred... Because I think it could have gone one of two ways for us.. but I think quite early on in the journey we shifted our focus and also never lost hope.”



Finding A Way

The sort of hope that gets us through

How will we live the life in which we find ourselves? What sort of attitude do we need to face the world, our future and ourselves; that will get us through the tough times and still leave us able to enjoy the good times.

For much of our lives we don't have to stare reality in the face and it doesn't force us, like a mirror, to stare back to look at ourselves and whether we are up to facing the problems we are facing.

But sometimes we do have to stare reality in the face and the problems are too big, too difficult and threaten those we love too much. We cannot just look away. We have to face reality and keep facing reality day after day, week after week.

But we also need something to keep us going; some point to the struggle, some sense in which what we are doing makes a difference, some way of seeing a path ahead and help for us to walk it.

We often call this hope, or optimism, or resilience, or just 'sheer grit', to put one foot in front of another.

If we don't face reality our hope just doesn't 'cut it'. It might last for a while but the façade will fall away, the make-up comes off at the end of the day and the problems in the wall we painted over show through the paint. We just have wishful thinking.

If we have realism without hope, we find we are stopped in our tracks with nothing but the size of the problem and our inadequacy to solve it.

The hope that matters is not wishful thinking. The realism that matters is not merely the facts. We need a tough sort of hope that looks at what can be done and can't be done, and focuses on the 'can', or even the 'maybe'.

I want to suggest three simple rules to get through this time.



Finding A Way

The sort of hope that gets us through

1

**Face as much of the problem with our child as we can
but let people know when we cannot take further bad news**


Truth is like medicine.

It may have to be taken, but takes time to work out the right

dose,

at the right time and with the right person

administering the 'medicine'.





Finding A Way

The sort of hope that gets us through

2


Take time to look at what part of our child's problems can be changed with treatment and what parts cannot

Focus our efforts on what we can change and what others can help us change and slowly work on accepting what parts of our child's problem we cannot change.

This is simple to say and hard to do.

Change is hard. Acceptance is hard.
Knowing what to change and what to accept is hard.

This rule is a simple rule but it is not an easy rule.





Finding A Way

The sort of hope that gets us through

3

Rest, restore and re-group ourselves with the rest of the family

Change what we can as we can for our child. Don't fight unwinnable battles. Understand what we can as we can. Don't make it all about us.

Find the help and back up we need as we can. The help will never be enough. It will never be just right. It will never give us a normal life.

But it will get us through over time.

And then rest (exhausted people don't have anything to give), restore ourselves (outrage and resentment injure us) and re-group with the rest of the family (doing it together stops everything falling apart – even if the 'doing together' is not as 'good' as we would do it alone).



Finding A Way

The sort of hope that gets us through

Summary

Face what we can, when we can



Focus on the parts of their lives that we can change; focus on the parts of their lives we cannot change and must accept



Rest, restore and re-group ourselves with the rest of the family



Finding A Way

The sort of hope that gets us through

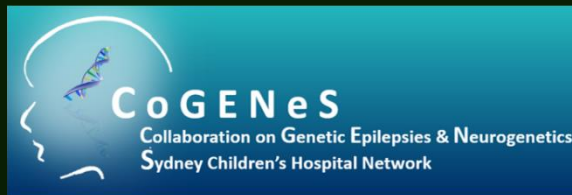
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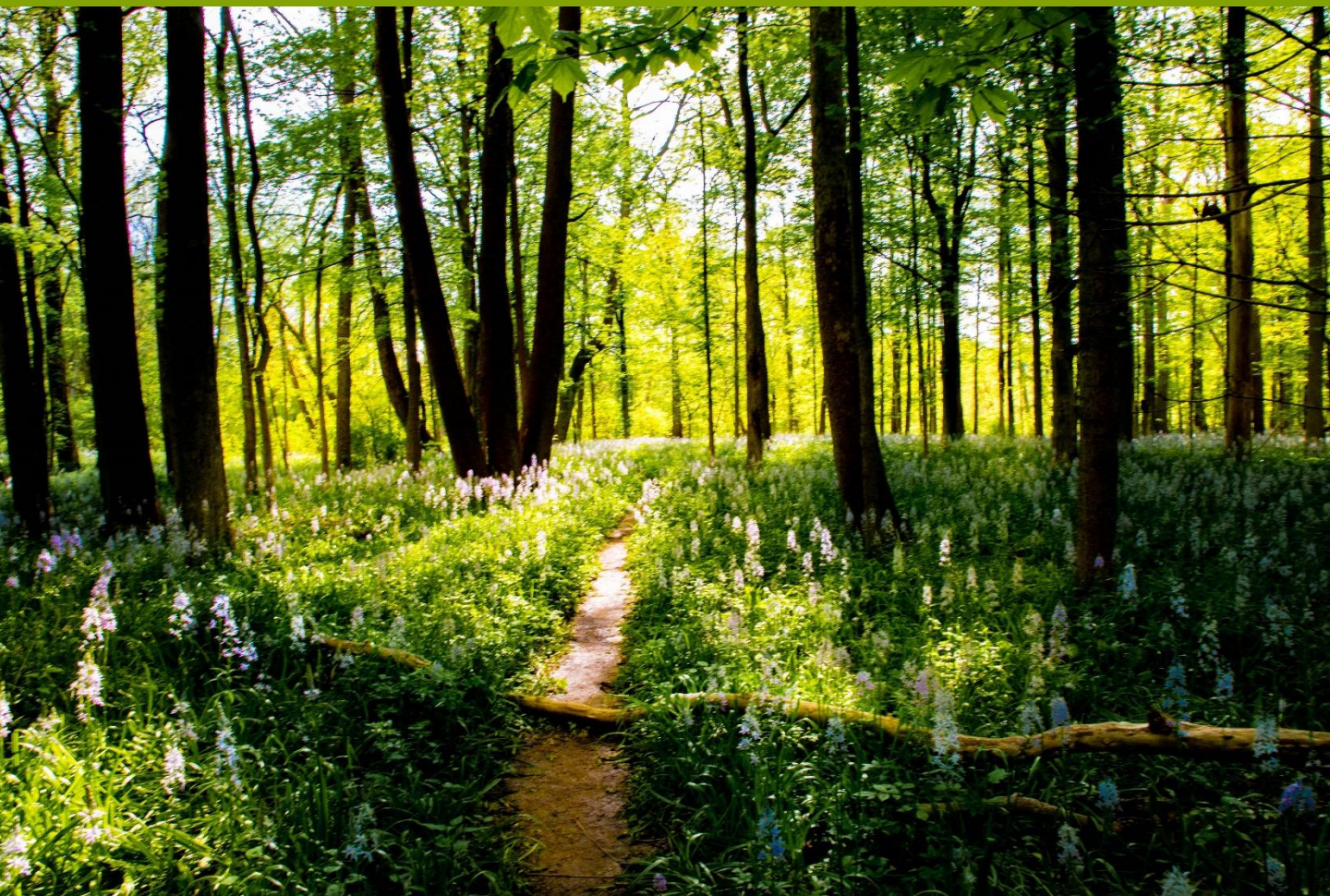
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Finding A Way



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