

Parenting a child with an undiagnosed genetic condition

You and your emotional
wellbeing



Parenting a child with an undiagnosed genetic condition: looking after your own emotional wellbeing

Undiagnosed genetic conditions can impact children in very different ways. As a result their impact on you and your family can also vary widely.

Your child may have lots of very obvious needs and differences from the time they are born. Others may only become apparent over time.

Parenting, although rewarding, can also be challenging at the best of times. There are also some additional aspects to being a parent of a child with an undiagnosed genetic condition.

These include:

- Lack of awareness amongst people such as healthcare professionals
- Looking for a diagnosis

- Managing uncertainty
- Managing logistics such as care and appointments
- The impact on family relationships

Looking after your own mental health and wellbeing is important for you as an individual in your own right. But positive mental wellbeing also helps you to look after your child, and other members of your family too.

This booklet is designed to help you hold this in mind, and makes some suggestions as to how to do that.

Early days: post-birth, or as you become aware of your child's differences

Coming to terms with the fact that the situation you find yourself in, might not be the one you pictured, can bring up lots of different feelings.

It is not unusual to feel worried, frightened about the future, or angry and upset about something happening to you that was outside your control.

You are not alone. There are voluntary organisations and parenting groups that will understand, and support you.

What can help?

- **Try to accept difficult thoughts and feelings**, rather than deny or feel bad about them.
- **You are processing a lot of new information, and experiences.** This can feel exhausting. Take time out if you can by engaging in activities that are relaxing, or distracting.
- **Treat yourself gently.** You are getting used to being not just a new parent, but a parent of a child you may not have anticipated.
- **If you have been through a particularly difficult time**, do reach out for professional support such as counselling.

Coping with a lack of awareness from others

When your child does not have a defined diagnosis, some friends and family members might be very supportive, but some may find it hard to understand or accept your situation.

Similarly, some professionals might be very supportive, others less so.

You might experience:

- your concerns being dismissed, denied or minimised
- disappointment with people you had hoped would be more supportive
- lack of access to the support that is available for diagnosed conditions
- being told you are an 'over-anxious parent'
- advice that is incorrect, or just not appropriate for your child

These experiences can be very upsetting and frustrating.

What can help?

- **Think who is good for what?** For example, some people may be helpful for practical support, others for emotional. Try to be aware of this and make decisions accordingly
- **Having just one or two people** you feel really understood by, can make all the difference. If you do not have this, a professional counsellor can help you feel less on your own.
- **Seek out support networks** that understand and share your experiences. As well as offering practical advice, they can help you feel less isolated.

Searching for a diagnosis

This can become very pre-occupying, and time consuming. Try to pace yourself.

Try not 'google' information or do research very late at night. We are often more emotionally vulnerable, and less resilient at that time of day. If it is making you anxious, take a break, talk to someone, or schedule other times to look at these.

This might apply to social media too.



Couples and family relationships

You and your partner

Some people find their relationships become stronger as a result of having to come together to support your child. However, parenting a child with additional needs can also be very stressful. Conflict over issues like roles and responsibilities, parenting styles, or relationships with wider family can be very common.

Adapting to the new demands - and feelings - of being parents together of a child with an undiagnosed genetic condition takes both time and practice.

Being a step-parent, same-sex or polyamorous parents, a solo-parent, or parents of colour also means there might be additional pressures on you. These could include stigma, or upsetting assumptions about you, or circumstances. Having a network around you that understands your experience from these perspectives too can be very important for your emotional wellbeing.

Children with undiagnosed genetic conditions can often need a lot of additional care and attention. There might be lots of hospital visits, or other appointments to get to. You might be worried about the impact of this on other children in your family. The charity **SIBS** (sibs.org.uk) has lots of advice and support about supporting siblings.

What can help?

- **Try to make time for yourselves as partners not just parents.** Do things together that you enjoy, however small.
- **Learn ways to healthily resolve conflict.** This might feel difficult. However, it will help both your own mental wellbeing and your quality of life. There are some organisations with resources that can help at the end of this leaflet.
- **Schedule a weekly check-in time** with each other to help you both connect, and discuss the practical tasks of the upcoming week
- **Be patient with yourself and each other.** You are learning not just how to parent together, but parent a child who may be different to the one you anticipated.



Relationship resources

Relate (relate.org.uk) has a range of resources including self-help guides and books for coping with common relationship issues including parenting problems.

Every Mind Matters (nhs.uk/every-mind-matters/lifes-challenges/maintaining-healthy-relationships-and-mental-wellbeing/) is the NHS campaign for mental wellbeing. It also has a healthy relationships section.

With healthcare professionals: PALS (Patient Advice and Liaison Service) (nhs.uk/nhs-services/hospitals/what-is-pals-patient-advice-and-liaison-service/) help you navigate NHS services, or support you if relationships with healthcare professionals have broken down.

You and your feelings

Your feelings about your child, family life or situation will naturally fluctuate and change over time. They might be particularly strong in the early days, or in certain situations. You might even feel some of them are bad or wrong.

Try to hold in mind that all feelings are valid, even the ones you don't feel very good about.

Some common ones include:

- **Sorrow, anger or grief** about what your child struggles with that other children do not, or about the changes to your life or relationships
- **Frustration** with services, systems or professionals that cannot provide what you need
- **Disappointment** with people who do not understand or offer help
- **Envy** about family lives that seem easier, or more what you had hoped for

Some parents also describe how having a child with an undiagnosed genetic condition helped them see themselves, or life, in a way that felt unexpectedly positive too. This includes feeling stronger as a person, or making changes to life that were initially unwelcome, but felt very meaningful over time.



rareminds.org/wellbeing-hub/you-and-your-feelings/mindfulness-relaxation-coping-strategies/

Coping with difficult feelings

You might feel like pushing away difficult or uncomfortable thoughts and feelings. However, this can sometimes make them stronger in the long-run, or emerge in ways that you do not feel good about.

Sometimes difficult feelings have to be put on hold for a while. This might be so you can get on with caring responsibilities, or cope with a particular situation. However, making time to process your emotions at some point is important for your mental wellbeing over the longer-term.



rareminds.org/wellbeing-hub/you-and-your-feelings/mindfulness-relaxation-coping-strategies/

What can help?

- **Make time for difficult feelings by:**
 - Talking them through with someone you trust
 - Writing them down in a diary, or journal
 - Learning a technique like mindfulness
 - Listening to music, or making art (that might reflect how you feel, or offer an alternative)
 - Doing a physical activity such as walking, dancing or sport
 - Having a good cry
- **Remember that all feelings pass in time**
- **BOX breathing** is a very helpful technique for coping with difficult thoughts and feelings when they arise
- **54321** is a good technique to help feel calmer, or manage strong feelings
 - (rareminds.org/wellbeing-hub/you-and-your-feelings/mindfulness-relaxation-coping-strategies/)

Managing logistics, and financial pressure

Managing your child's health or care needs, juggling these with work and family life, your own needs, and possible financial pressure can be very stressful.

Sometimes there are big changes. These could be in your work-life balance, your role in your family or relationship, where you live, or how your home is organised. These can all impact on your personal identity too.

You are not alone. Many parents will have faced similar situations and challenges to you.

They are often very pleased to share advice, and offer support.

What can help?

- **Try to talk to other people** you trust, and who know you, about any big changes or decisions. Sometimes professional counselling can help too.
- **Seek out advice** from relevant organisations such as parent-carer charities to make sure you are applying for all the support you might be eligible for (there is a list at the end of this leaflet).

Finding your support network

Building a network of support around you will be important for your own mental wellbeing.

This will help you feel less on your own too. Making time for your own needs is very important when you are also a parent-carer.

It might include:

- **Supportive family members and friends**, and these might not always be the ones you imagined at the start
- **A support group or community** to help encourage you, share knowledge, and feel more confident about your parenting such as groups for parents of children with general or specific disabilities, neurodiversity etc. These might be local, or online.
- **Meeting up with others** around your own personal interests or hobbies such as sport, exercise, book groups, music/singing, craft groups etc
- **Faith-based or culturally-specific groups** that can offer both practical and emotional support, and understand your unique perspective and experiences
- **Respite care** (formal or informal) can help you re-charge emotionally and physically, particularly if your child's care needs are high. This is not always easy to access, but try to persevere. Your local council should be able to advise you what is available locally

Join the **SWAN UK** (geneticalliance.org.uk/support-and-information/swan-uk-syndromes-without-a-name) community to connect with other families who understand the unique challenges of raising a child affected by a syndrome without a name.



Online groups can be very supportive. If they feel too much at any point, give yourself permission to step-back.

Managing uncertainty

There can be a lot of uncertainty with undiagnosed genetic conditions. This might be both in daily life, but also about the future.

This can feel very difficult to get used to.

Receiving a diagnosis may ease one lot of uncertainty, but often introduce others as a result.

As time goes on, you might find that you become more used to living with uncertainty. The feelings of worry, anxiety or frustration that go with it may also become easier to manage too.

We often cope better than we imagine with difficult future events.

What can help?

- **Try to be specific** with yourself about what you are worrying about, or frightened of
- **Ask yourself** if this is something you can control, influence, or find out more about
- **If yes to any of the above**, then take steps (either now, or when you feel ready) to address these in a way that helps you feel more prepared, or reassured - ask for help and advice as needs be
- **If no**, try to bring yourself back to focus on the present moment - rather than focus on a future event that is not happening right now
- **Mindfulness-based techniques** can be very helpful - there are some links at the end of the booklet
- **Rareminds Wellbeing Hub** also has a whole section on Uncertainty, Change and Loss

And ... remember the basics!

It can be all too easy to side-line your own physical and mental health when you are a parent-carer.

Taking care of yourself is important in its own right for you as an individual. It also helps you look after those you care about.

Rareminds Wellbeing Hub

(rareminds.org/wellbeing-hub/) has a range of resources including on living with uncertainty, change and loss, relationships and finding support.

Rareminds Wellbeing Hub



Remember:

- **Eat:** Try to make time to eat as healthily as you can, even when time is short
- **Drink:** Keep hydrated. This helps maintain energy levels. Keep an eye on alcohol use. Take action if this starts to increase
- **Rest:** When your sleep is disrupted, rest or nap during the day as best you can
- **Exercise:** supports both your short and long-term physical and mental health. If it is hard to fit into your day, try to build stretching and movement into your everyday activities
- **Connect:** make time for those that nourish you, but try to limit time with people who drain you, especially when times are hard
- **Make time for fun:** this will help you keep going on difficult days, as well as in the moment
- **Be kind to yourself**

Resources

General mental health and wellbeing support

The Hub of Hope (hubofhope.co.uk) provides details of all the types of mental health support available in your local area.

The NHS (nhs.uk/nhs-services/mental-health-services/how-to-find-local-mental-health-services/) has lots of advice. Calling 111 will also provide access to local services, advice, and sign-posting.

Mindfulness is a very practical approach for helping to cope with a range of difficulties including stress, uncertainty and difficult feelings.

Counselling and mindfulness

Mindfulness (nhs.uk/mental-health/self-help/tips-and-support/mindfulness/) The NHS website is a good place to start finding out more about Mindfulness. The Rareminds website also has some short videos of simple exercises to learn.

Counselling can provide a safe, confidential space to talk through difficult situations or decisions, or cope with difficult thoughts and feelings. Counselling can be available through the NHS, charities or privately. There are lots of different types of counselling, including couples counsellors and family therapists. Finding the right therapist and type for you is important. The British Association for Counselling and Psychotherapy website (bacp.co.uk) has lots of information, including how to find a therapist.



SWAN UK supports families affected by a syndrome without a name – a genetic condition so rare it often remains undiagnosed. We are the only dedicated support community for these families in the UK and are run by the charity Genetic Alliance UK.

Parenting and family life

Affinity Hub (affinityhub.uk) is a network of support and advice for parents of children with disabilities.

Contact (contact.org.uk) is a leading support charity for families with disabled children.

Family Action (family-action.org.uk) provide support and resources for families of all kinds, including a phone and text helpline if you are feeling overwhelmed, upset or in crisis .

GingerBread (gingerbread.org.uk) is a leading UK charity for solo-parents with a wide range of resources.

The LGBT Consortium (consortium.lgbt/about-us/) supports and signposts to a range of LGBT groups and organisations

Unique (rarechromo.org) is the charity for families with rare chromosome and single gene disorders. A lot of their advice and information is also relevant for undiagnosed children, and their parents.

Carers Trust (carers.org) provides practical resources and advice for carers of all kinds on a wide range of issues, including sign-posting to local groups.

Crisis support for your mental health

In an emergency, go to your nearest A and E or call 999. If you need non-urgent help, call NHS 111 for advice and referral to your local mental health support service.

Helplines:

Samaritans: 116 123 (free to call) or jo@samaritans

SHOUT: Text 85258

CALM: 0800 58 58 58 plus livechat and WhatsApp

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