### **Emerging Minds Families**



#### **Definition**

We know that families come in many forms. For the purposes of easy reading, the term 'parent' includes the biological, adoptive, foster and kinship carers of a child, as well as individuals who have chosen to take up primary or shared responsibility in raising that child. We also appreciate that every child is unique and has different strengths, vulnerabilities and experiences that shape their health and development.

#### Money, housing and health

This fact sheet is part of a series we created with families who've experienced tough times to give you new ideas for how to get through health and money struggles as a family. It's always hard when family members are sick, especially if it happens suddenly or they are ill for a long time. If we're dealing with other difficult things at the same time, such as not having enough money, homelessness, violence or discrimination, it can feel overwhelming, like a big wave or a set of dominos toppling down, one after the other.

Unfairly, families that are going through these difficult things are more likely to experience health challenges. And vice versa, health challenges can make families more vulnerable to financial struggles, along with experiences of homelessness, violence or discrimination. The coming together of these things creates injustice.

Despite this injustice, whenever families experience illness, health issues or disability on top of other challenges, they find ways, big and small, to get through, stick together and focus on what matters to them.

### Impacts on families

We asked families who've experienced financial difficulties while living with chronic illness, mental health challenges, disability, unexpected big and small health crises, and often more than one at the same time, what helped get them through.

We hope the following stories remind you about the skills your family is already using to get through tough times and give you some new ideas too. Everyone's circumstances are unique so these ideas may not fit your family, but we hope the stories shared help remind you that you're not alone.

### **Juggling costs**

When we don't have enough money and our families are facing health challenges, we constantly have to make hard choices like:

- How do we pay for appointments, medication and bills?
- How do we put food on the table?
- How do we get money from one source to pay another?
- What do we do when a working family adult is unwell, or has to care for other family members, and can't work?

Caring for a family and surviving is hard enough on a welfare payment; add significant medical and other health costs and it can feel impossible – a constant juggling act. Many parents or carers are unable to work, can only work part-time, or have to miss work regularly because they have the responsibility of caring for others and/or their own health challenges, which can mean earning less income at times when it's needed most.

These difficulties are increased for:

- families that live in rural or regional areas and have to factor in additional time and costs for travelling to access health care; and
- new migrant families that might be having to learn how to navigate a new health care system, and at the same time their home currency might be worth less than the Australian dollar.

#### Lifelong parenting

Many parents will be involved in active parenting for a couple of decades as their children journey from birth to adulthood. But others have active parenting roles their whole lives; especially parents of people who are unable to live independently due to illness, disability or chronic mental distress; or those who care for grandchildren or other children for multiple generations. This can mean being under much longer-term financial strain, with additional stress and decisions to make when experiencing a health crisis.

# Single parents having to make difficult choices

Single parents who don't have family or friends that they can rely on often have to make difficult choices, compromising on caring for their own health or showing up as a parent in the ways they really want to. When we can't take time out to recover, what do we do? When we have no choice but to spend the day in bed, how do our children get what they need? It can mean not being involved in their schooling, which can lead to our children missing out on opportunities or getting support for challenges that come up.

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My mum is a single mum and couldn't stay with me because she needed to work. She got sick and she still needed to look after me and work hard at work too ... She was worried for me and I was worried for her.

YOUNG PERSON, VICTORIA, IN CHECKING IN WITH CHILDREN AND YOUNG PEOPLE<sup>1</sup>

### Children feeling like its their fault

Sometimes children can feel responsible if:

- they require a lot of care from others because of illness, disability or mental distress
- they themselves are carers of other family members; or
- they see the family struggling with the effects of health difficulties.

It can be a heavy responsibility to carry and feel isolating when other children and young people don't understand family illness or disability. And it may feel like they have to grow up too fast. In trying to make sense of the unfairness of their family's situation, children may think they are a burden, that the illness is their fault in some way or that it's their responsibility to fix things.

### **Pressure on relationships**

Health challenges in families that are under pressure in other ways can make it harder for everyone to feel connected and present. It may lead to family members feeling out of sync and not knowing what's going on for each other, so when health crises occur it's harder to feel like everyone's on the same team.

When the family is stressed by difficult circumstances or feeling sick, fearful, angry or frustrated, resentment and violence can increase. Family members can feel like they are fighting against each other instead of fighting alongside one another. And often children are seen to be 'misbehaving' by others who don't understand the context of their lives. It puts lots of pressure on relationships within and outside of families.

## Take a moment to think about...



- What impacts has your family experienced that were not included in this list of impacts?
- What kinds of things do you and/or your children do to prevent, prepare for or get through times when one or more of you is unwell?

# Skills of families getting through tough money and health times

Even in the most challenging circumstances, families are always responding and finding ways to get through, often in unseen ways.

#### Making room for relationships

'When I feel unwell, I often really need the kids to give me some space. But I am also aware that at these times the kids often need more support as well. The glue of the family starts to fall apart. Who will help us now? We have reached out to organisations for support. We never found financial support, but we found social service organisations who were able to come in and help the family keep functioning and keep the family together. When these supports come in, it takes away a bit of the stress, and makes more room for relationships.'

## Take a moment to think about...



 How do your relationships with your child(ren) change when someone is unwell? Who or what supports you in these times?

#### Tuning in to children's emotions

'Noticing changes in routines and behaviours can be a sign kids might be struggling. For example, one of my kids will go very quiet and internalise everything. Another child would be very emotional, aggressive and started wetting the bed. Sometimes sibling fights started up. These were signs I needed to talk to my kids and figure out what was going on.'

## Take a moment to think about...



- What happens for your child(ren) when they are upset? How do they show you that they are stressed or upset?
- How do you talk to your child(ren) about their worries? What do you do to respond to any worries they have?

### **Talking to children**

When our families are facing lots of challenges it can be tough on the children as they try to make sense of what they are seeing, hearing, thinking and feeling. We know children sometimes blame themselves or have thoughts they keep inside. Talking to them about health challenges can:

- strengthen trust and relationships
- help children understand that it's OK to talk about it
- reduce worries and concerns; and
- allow them to ask questions and get the correct information.

The British Psychological Society provides advice on talking to children of different ages about illness.

#### Deciding what to share with children

'I remember I used to try to hide my feelings in front of my child. When I needed to cry, I used to put him in a pram so he can't see me. Sometimes I think differently now, I think if I explain that "Mummy is sad, that's natural, that's normal", it's better. For me it was more difficult to always hide it from him.'

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A lot of people say you should be transparent with your children, and you should, but you shouldn't explain everything to them. They are still kids and they don't need to know everything. The things that I did need to know were the practical things, for example that Mum needed to be left alone for a while. Or when my sibling was really sick as a baby and was in hospital, it was explained to us that she was sick and in hospital for help. We didn't know how bad it was or how bad it could be - she could have died - we just knew what we needed to know at the time, day to day, so we could make sense of what was going on.

ELLIOT, YOUNG PERSON, LOOKING BACK ON THEIR CHILDHOOD EXPERIENCES, KAURNA COUNTRY

## Take a moment to think about...



 How do you go about deciding what to share with your children? What do you weigh up?

#### **Routines and rituals**

A number of us find rituals and routines important during difficult times.

'One ritual we had for many years was our Sunday pancake ritual. Every Sunday we would have a slow start to the day and I would cook a huge batch of pancakes that we would all sit down as a family and eat. This went on for almost every Sunday for years.'

'Our routine is to have an afternoon tea on the weekend. We might have a discussion or play a card game. It is a time to say what we need to say.'

'I try to keep a bedtime routine with my son. It helps him know what to expect every day, and it also gives me more time in the evening to myself to try and figure out what supports were out there.'

## Take a moment to think about...



- What is working for you with routines for sleeping and mealtimes? What do you find challenging?
- Who could you reach out to for support?
- Are there ways that some of your child's routines can continue when health challenges get in the way?



RACHEL, NINE YEARS OLD

#### Coming up with shared language

Sometimes it can be helpful for a family to have a shared language that helps family members know how to respond to different situations.

'I have different conditions and each one has similar things, but slightly different things. I might say to the kids "I'm having a PTSD moment": that's shorthand now for all the things that go with that, and they'll know how to manage that situation. Or I might say, "I'm having a masto [mastocytosis] moment," and that's shorthand for another set of things.'

#### Being like a warrior

One of us found that when a situation was very serious, it was helpful to think of themselves as a warrior.

'My son was born with this serious heart issue when I was pregnant, they asked me to terminate. I didn't accept. And he went through a big heart operation, then he was in intensive care for 10 days. But it just changed me as a person. I was ready to fight. My son was very little. I was like a warrior, I was just there for him. I couldn't sleep and eat for a couple of days. It changed me to a stronger person. I am much stronger.'

You might like to read <u>Connecting and caring for</u> <u>each other in tough times</u>

#### **Having outside support**

'Years ago when I was going to hospital – the kids were really tiny then – we had my mother-in-law staying with us, and she was very supportive of my partner: that's what helped her get through, was having somebody here that could help her with the children and that could give her moral and emotional support when I was unable to provide that for her and the children. The kids have grown up and they've seen that modelling, I think that's sort of become a part of who they are – they're very caring, they're very supportive.'

You might like to read <u>Feeling connection and</u> <u>belonging outside our families</u>

#### **Checking in**

'I spent a lot of years in bed and having that paranoid feeling that nobody cares. But people were always checking on me. I look back on that and realise, they really cared about me. And so as I've come out of that, I'm really mindful, especially with the kids, to make sure that they're OK. I don't do it in a naggy way, I just knock on the door, ask: "How are you feeling? You OK?" If they need something more, I'm happy to provide. Sitting with them, little things. They voice it and I encourage that a lot. Nothing gets fixed if you don't have a solution to the problem, you can't have a solution if you don't know what the problem is.'

#### Children's caring skills

Children can be active participants in the lives of their families, working together to get through tough times.

'Because we experienced homelessness when the kids were young, and I've been a single parent more than I've been a coupled parent, the kids really had this sense that "We have to look after mum." We didn't have a home, there was not that structure and stability. "We've only got mum." And for a time I was very much in very deep trauma - a lot of times, I really couldn't function and sometimes I couldn't talk. They kind of learned, early on, how to look after Mum, how to manage situations, what to do to jump in when they had to. And maybe that started from necessity, but then it kind of became out of caring and love. And I do spend some time feeling, "Am I burdening them?" But I actually think it's a positive thing. For them to be able to say, "Yeah, I helped my mum when she really needed it, and I was only little, but I did it." What a beautiful thing that is for that kid to be able to have that experience and that memory.'

#### Asking for practical help

'I struggle to ask for help, I want to do everything myself until I drop, you know? I'm getting a little bit better. The worst thing that happens is hearing: "No, I cannot." But, you never know, you might get support.'

#### Asking for emotional help

It's normal for parents and children to feel and show lots of emotions – like anger, sadness, guilt and shame. Sometimes when we have issues of health and money and other things piling up we need support to help us make sense of and navigate these feelings together. If you feel like you could use some support, take a look at these

mental health crisis and counselling services.

#### Sometimes just do one thing on the list

'Sometimes with your to-do list, just stick with your priority and accept that you're not able to do everything. Just accepting that you're a human, and you're not always able to do everything by yourself. You just talk to yourself

like, "I'm able to do number one, which is important, and that's it. That's all I'm capable of doing. That's all I can do."

#### Finding a doctor who listens

'My GP [general practitioner/family doctor] is really good, she listens. Another example is I found out about a new medication and went to my psychiatrist and told him about it and he said, 'Yeah, let's give it a try.' And that was actually the medication that saved my life. So having someone who listens and supports you, having the right medical professionals makes a difference. Both these doctors bulk billed, which was huge.'

## Finding a doctor who bulk bills – or planning if they don't

'We had to search and search until we found a doctor who bulk billed. And we often book double appointments to make sure we can talk about all our issues.

'Now we need to see another specialist for my daughter and their fee is huge, we get some back on Medicare, but it is still a huge cost. We manage this by saving as much as we can in the lead up to these appointments. The appointments are every two months, so we know we need to save in between.'

#### Having a plan for crisis

'I had a mental health care plan on the fridge when I was unwell; it had everything listed, anything that I needed people to know, it was all in that plan. It was there for the whole time that the kids were growing up just in case I ever had to go back to the hospital. That was one of the things that was really important to me, knowing that I had that there so that anyone – like a carer or my wife or whoever – could come into the house and just read that and go, "OK, this is what we need to do with the kids", and get it done.'

'I know these things are not always possible for everyone, but it helps to save money for a crisis or urgent situation. When I get paid I put a small amount aside and then pretend I didn't receive it. It is very difficult, but it is possible. Or think of a friend who is able to help. I had days that I didn't have anyone. I didn't know what to do. I was in a mess. So if you can, have a bit of plan for a crisis.'

# Take a moment to think about...



- What stands out to you from reading these stories? Are you reminded of things you do to cope with health and money challenges in your family?
- Who or what supports you in similarly tough times?

#### Dive deeper into podcasts

Telling children about a parent's cancer can provide reassurance, not just for them, but for the whole family. The Cancer Council NSW's Explaining cancer to kids shares some different ways to talk about a cancer diagnosis with your children.

In <u>Parenting through health challenges</u> Jen talks about how she supported her children when she had COVID-19, cancer and heart failure.

The Royal Children's Hospital in Melbourne has a podcast series called <u>Life</u>, <u>Love and Loss</u> for families caring for a child who is dying or are likely to have a short life.

You can thrive with chronic illness and special needs talks about living with ADHD, depression, chronic illness, anxiety and suicidal ideation in the family.

# Services and resources to help families facing health challenges

Health issues during pregnancy, birth and while parenting babies

Health can be a big issue for families at this stage of life.

- Parents and families seeking mental health support during pregnancy and in the first year of parenthood can reach out to <u>PANDA</u> (<u>Perinatal Anxiety & Depression Australia</u>)
- Families of children born prematurely and sick can seek support, friendship information and assistance from Life's Little Treasures

Parenthub lists some <u>support options for families with sick babies</u>.

#### While you're away: Care plans for children

Some of the parents who created this resource found care plans useful when they had to go to hospital or spend time away from their children for any other reason.

- Read about how to use Emerging Minds' care plans and if they suit you, there is a baby care plan and a children and young people care plan.
- Emerging Minds also provides support resources for <u>families where a parent is</u> experiencing mental illness.

#### **Carer support**

- Some of us also found the <u>Carer Gateway</u> useful to support family members with a caring role.
- There's also useful information available on the <u>Young Carers Network</u> and <u>Carers</u> Australia websites.

#### Parenting with a disability

- We've Got This: Parenting with a Disability is a podcast series by Eliza Hull that explores the complexities of parenting with a disability, while also challenging stigmas and stereotypes.
- You might like to visit your local library to borrow Eliza Hull's book <u>We've got this</u> about the highs and lows of parenting with a disability.

#### Speaking up for change

- If you can, you might want to contact your local Member of Parliament (MP) or council to let them know about the barriers you are up against and what kinds of things might make a difference.
- You can <u>search for your federal MP</u>, or type 'who is my state MP' into Google and follow this guide on <u>how to write a letter to your MP</u>.

#### **Books**

You may also be able to borrow titles on this <u>list of books about family illness from your local library.</u>

# More money, housing and health resources

Have a look at the following options and choose what feels right for you and your family.

- Experiences and skills of families living in poverty
- Supporting children when you're struggling with money
- Talking to children about family money struggles

AVAILABLE HERE

View all Money, housing and health resources



Are you a practitioner wanting to share this resource with a person or family? First check out our practitioner guide.

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#### References

Commission for Children and Young People. (2021).
 Checking in with children and young people: Youth survey, November 2020 to February 2021. Melbourne: CCYP.

