


MAST CELL
ACTION

PARENT SUPPORT LEAFLET

FOR PARENTS AND CARERS
OF CHILDREN WITH MAST CELL
ACTIVATION SYNDROME



WELCOME

TO THE MAST CELL ACTION WELLBEING LEAFLET FOR PARENTS

This leaflet has been developed to help support parents and carers of children living with systemic mast cell activation and Mast Cell Activation Syndrome (MCAS). It provides suggestions for how to care for your personal mental wellbeing whilst caring for someone with MCAS, and shares ideas and suggestions for how to communicate and support each other as a family.

Experiencing challenges to our mental well-being and mental health are a common part of being human. This can range from the worries that we all experience as part of everyday life, to more serious conditions where we might need to seek extra support and specialised help.

We also know that challenges with our mental health and wellbeing can be especially magnified when dealing with chronic health conditions.

MCAS is a particularly challenging condition, with many people experiencing difficulties in understanding the condition themselves, explaining it to others and finding informed professionals who are able to recognise and diagnose the symptoms.

Even following a diagnosis, identifying the right treatment can also present its own challenges. It is therefore not surprising that living with this condition and/or caring for someone with the condition can impact relationships, your ability to cope and your overall mental and physical health.

It is understandable that parents may experience a number of negative emotions. The life they envisaged and the relationship they expected with their children may be impacted. For example, family trips or bike rides – things that may appear uncomplicated for a 'typical' child – can require extra planning and result in anxiety and even fear. However, just because these experiences are not as imagined does not mean that we cannot find new ways to have special experiences.

In this leaflet, and other resources, we hope to share ideas and suggestions that support a positive way of thinking and approaching a new way of family life, whilst accepting the challenges that may lay ahead.



COMMUNITY QUOTES

Other parents from our MCAS community would like to share some of their feelings and experiences with you:

"I don't know why I feel angry.

Nobody put us in this situation so it seems odd because there isn't anyone to be angry at, but I am angry that this is happening to us."

"Some days I feel like I have got this and other days having a child with MCAS is just too much.

The unknowns for the future, the unpredictability, the thoughtless comments from others and the glares from people when you are checking labels and administering medications out in public. The strain on mine and my partners relationship; the constant anxiety."

"He's far braver than me.

I shed far more tears for him than he does for himself - he's used to feeling ill now. He doesn't really know any different, and that makes me very sad."

It is vital that you look after yourself at the same time you are looking after others around you. It can be challenging to support a child with additional needs and accessing support could help alleviate some of these challenges.

In addition to this leaflet and accompanying materials, a variety of resources for you and your child are also available on our website, www.mastcellaction.org.

RECOGNISING AND DEALING WITH SPECIFIC FEELINGS OF...

1. GUILT

Guilt is a completely understandable emotion to experience, but it is really important to understand that you are not to blame. You didn't choose or cause this, and any feelings of guilt are an indication of the care and love that you feel for your child.

Caring for a child with additional needs can be emotionally and physically exhausting. In order to do this well, you need to take especially good care of yourself. You shouldn't feel guilty for taking time for yourself when you need it. In fact, you should feel that taking time for yourself is the right thing to do. In an emergency, you always need to put your own oxygen mask on first. This is important to remember, as you cannot give to others what you don't have yourself. Find ways to refuel and top up your tank and ensure you take the opportunities for self-care.

2. STRESS & OVERWHELM

Being stressed and feeling overwhelmed are very natural experiences. You might find it helpful to make a list of what you feel you have to do; identifying what you can control and writing these down. As human beings, we often find comfort in predictability and routine, and this can make us feel safe. Living with a condition that causes sudden and drastic change is stressful. Learning to focus on what we can control can reduce feelings of helplessness. Perhaps using a diary or planner and looking at the time you have available (and identifying what you can potentially give away to others) may help. Sometimes thinking about the things we have to do can be more overwhelming than doing them and we often have more time than we think we do.

We have included a 'Perceived Stress Scale' tool on our website to help you to assess how well you feel you are coping with the demands of your day-to-day life and to give you an idea of your current level of wellbeing. Seeking additional resources and support (what you can give yourself back) is always very important to balance your life. Ensuring that these natural experiences do not become more permanent is also vital, as living with long term stress can give way to stronger feelings of anxiousness and depression. Please don't hesitate to seek more specialised help if you need it.

3. ANXIETY & HYPERVIGILANCE

Anxiety because of MCAS might be something that your whole family is feeling, as this is a challenging and often unpredictable condition to live with. It may help to remember that anxiety (and vigilance) is an important way the body and mind works to provide us with protection, and helps us to avoid things that could be dangerous. For example, our body reacts to pain to warn us there is a problem. Our mind is wired for fight or flight to protect us against threat, and stress can be a useful part of being human. Being vigilant is a sign of being a good parent and it is natural to want to ensure the safety of your child. However, being hypervigilant and overly anxious can be detrimental to your physical and mental health. It is important to find a balance between reducing possible threats, whilst preserving your child's independence and a curiosity about the world.

With MCAS, threats to children are changeable and often different from their peers. There are ways you can help to take control of the environment and make yourself and them feel safe and calm. It can also be useful to reflect and take time to figure out what is a real and what is a perceived threat.

Sometimes when we have been living with fear and anxiety for a long time these emotions can become "hard wired" into our brains and bodies. There are things that we can do to start to create more positive pathways and thoughts in our minds. In particular, finding ways to look for the positives, rather than seeing and feeling the negatives. We have provided ideas of things that you might enjoy doing as a family to build this positivity further on in this leaflet.

4. DEPRESSION

Depression is a common mental health issue, which can be triggered by stressful events. Being concerned for the safety of your child could understandably impact your mood. It can be helpful to identify any potential triggers for depression.

In some cases, there can be a physiological or physical explanation for feelings of depression. For example, lack of sleep or sunlight (as we see in seasonal affective disorder). In such cases psychological approaches might not be as helpful, and it would be better to address the underlying cause, such as improving your sleep. Changes in our mood can also be impacted by things we are not aware of i.e. air pressure, lack of vitamins or changes in the weather. Keeping a journal can be useful in tracking mood, identifying early signs of change and noticing when your mood is lifting. This can help to give hope and show progress.

Feelings of loneliness and isolation can negatively impact depression and anxiety. Unfortunately, when we are depressed we are less likely to reach out and talk to others who could offer us the support we need. When we are feeling depressed, intrusive thoughts may be common and also prevent us from reaching out, for example; "I am a burden" or "I need to deal with this by myself".

It is important to remember that our depression-based thinking is often not accurate and you are valuable and doing the best you can. Finding useful ways to remind yourself of this can help. Just remember that the storm will pass.

It is not uncommon to have intrusive and even suicidal thoughts when feeling depressed or anxious. Speaking to others about our thoughts can help to normalise and soothe them. However, should these thoughts become regular, persistent or if there is a change from thoughts of suicide to the planning stage of suicide, please seek help.

The Samaritans can be contacted on **116 123** for free at any time of day or night.

Other useful resources include:

<https://www.mind.org.uk/>

<https://www.samaritans.org/>

<https://www.anxietyuk.org.uk/>

<https://www.giveusashout.org/>



Moving forward together

When we are feeling anxious, stressed or depressed it can be difficult to understand and manage our emotions. Sometimes when we lose control, it can amplify feelings of guilt, shame and overwhelm. Being kind and forgiving to yourself during this time is essential.

An important thing you might need to do is accept that you can't always just fix everything. But you can find ways to manage the best that you can.

Sometimes we need to remember the words that we say to our own children – that we can only do the best we can.

When we can accept reality, it can also help us to move away from feelings of suffering and being 'stuck' and embrace the possibilities of moving forward.

Communicating with each other

We have created a range of tools for communicating together as a family and helping you to share with each other what you are feeling and experiencing. It can be particularly difficult for young children to share how they are feeling and what symptoms they experience, leaving them having to rely on other people to understand their bodies. Hopefully, this can support them to find the language to talk about their own experiences of MCAS more effectively.

It can also be really difficult to untangle all the different things that are causing stress and anxiety. It can be helpful to separate out and identify what each of these are, so that you can find ways to address them. There is a great visual exercise on our website that uses the analogy of untangling the threads of a ball of wool. You could do this as a family to help each of you to share your worries and find ways to deal with them together.

Looking at the positives

Sometimes, it can take time to make progress – and moving forward may be built up from many small victories. It is really important to share the positives, talking about each of these small victories and celebrating anything and everything through 'mini celebrations'.

Another idea is to create a 'gratitude jar' where you capture and share the things that you are grateful for and can exchange notes of thanks and appreciation with each other.

Similarly, you could also create a 'feel good' jar that you fill with ideas of what would make you and your family feel good. Both of these ideas could also be part of your self-care / reflection journal.

Creating a positive way forward together can also involve recognising the 'cans' rather than the 'cannots' – thinking about what insights and tools living with a chronic illness like MCAS has given each of you. For example, compassion for others, resiliency, and an appreciation for the small things in life.

“One of the best things about having a child with MCAS is the joy and celebration in the smallest of achievements, especially those from battles which others don't have to face – I like to think that gives us more opportunities to celebrate than most! Now I try to see the best in even the darkest moments, because MCAS is something that my daughter lives with – it isn't the whole of her.

It also helps me to remember that everyone is facing an invisible battle – and every single parent feels guilty at times. My daughter's illness has helped to shape who she is becoming, she is filled with hope and determination and resilience. She has a compassion and empathy which I have never witnessed before. Not all of the changes that MCAS has brought to our life have been bad.”

MAST CELL ACTION

This is one of a range of support materials that we continue to gather together to help everyone affected by systemic mast cell activation and MCAS.

These are available on our website at:
<https://www.mastcellaction.org>

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