

# How can we support families affected by congenital cytomegalovirus (cCMV) better?



## 1. Our background

### CMV Action

CMV Action is the only charity in the UK providing support and information to families affected by congenital cytomegalovirus (cCMV). cCMV is the most common viral infection that can affect babies before birth, with potential long-term health impacts such as hearing loss, developmental delays and vision loss.

Despite the prevalence and potential severity of cCMV, awareness and knowledge are alarmingly low among healthcare professionals, parents and the general public. One of our key roles, therefore, is to develop and deliver resources and training for healthcare professionals, run public awareness campaigns, and collaborate with researchers and policymakers to improve outcomes for those affected by cCMV.

### Our aims

Our charitable aims are:

- To promote and protect the physical and mental health of families affected by cCMV through the provision of support, education and practical advice
- To advance the education of the medical profession and the general public about cCMV and its implications for the family
- To promote research into the causes, effects, prevention, treatment and management of cCMV and to disseminate the useful results thereof

### Our team

We are a small team made up of three part-time freelance staff and six volunteers. Our volunteers have lived experience as either a parent or grandparent of a baby or child diagnosed with cCMV. One volunteer lost a baby to cCMV during pregnancy and now offers support to parents experiencing this. Our volunteers bring first-hand understanding and empathy, which enhances the support CMV Action provides to families.

We have an expert team of medical advisers and virologist to support us – all with extensive experience in the field of CMV. They lead studies, conduct research and support the medical needs of families affected by the virus. Our medical advisers are:

- Professor Chrissie Jones, Consultant in Paediatric Infections
- Asma Khalil, Professor of Obstetrics and Maternal Foetal Medicine
- Seilesh Kadambari, Consultant in Paediatric Infectious Diseases
- Professor Paul Griffiths, leading expert in the field of virology and Patron of CMV Action

## Our community

We run our charity fully remotely, and the majority of our work takes place online with our beneficiaries and stakeholders in the UK. Therefore, our digital presence is paramount to achieving our charitable aims.

We run an online community support group for families on Facebook and 482 of our members are based in the UK. We also provide a support telephone helpline and email support to families and healthcare professionals in the UK. On average each year, we support around 250 individuals through telephone, email and online support services. We anticipate that these numbers will increase as awareness levels grow.

Our face-to-face training and workshops are delivered at educational institutions and health trusts in the UK. We are also members of an international CMV partnership alliance, where we regularly share good practice and learning.

## 2. Our future

### Our vision, mission and values

Our vision is a world where cCMV no longer poses a risk to babies and children. Until then, we will continue to support those who need us.

We want every:

- **person of child-bearing age** to know about cCMV at the earliest point, and ideally before becoming pregnant
- **health professional working with expectant parents, babies and children** to be aware of cCMV and consider this as part of their diagnostic assessment
- **newborn** to be screened for cCMV within the first few days of life
- **person affected by cCMV** to be fully supported by having their emotional needs met and given practical support at all stages of their journey

Achieving our vision and mission will be underpinned by our values:

- **We are proactive**  
We are purposeful about the directions in which we are heading, explore new possibilities and change paths towards self-chosen outcomes.
- **We are collaborative**  
We build strong relationships with the people and groups that the charity serves and works with.
- **We are accountable**  
We act with honesty, transparency and integrity in all aspects of the charity's work.
- **Evidence-based**  
We are guided by robust research and expert advisors to achieve the best possible outcomes for those we serve.
- **Inclusive**  
We ensure that all anyone affected by congenital CMV, regardless of their diverse needs, have equitable access to the support and resources they need to improve their lives.

### **Our strategy (2025 – 2028)**

**We are proactive.** In May 2024, we began work on producing our new three-year strategy, which we plan to launch in autumn 2024. Our strategy will put greater focus on the support and information we provide to those affected by cCMV and strive to build a stronger, resilient community.

We have identified seven priority areas that will guide our work over the course of the strategy, and we have begun to apply for grants to help us fund our developments in these seven areas:

- Advocacy
- Capability
- Community
- Information
- Research
- Support
- Training

**We are collaborative.** Over the next three years our telephone helpline, email support and online community group on Facebook will be part of a more comprehensive support offer to families, and it is crucial that this offer responds to the needs and experiences of the cCMV community. Our families survey is an important step in our understanding of what these are currently and might be in the future. We will continue to work alongside members of our community – and those not yet aware of our community – listening to their stories and being guided by what they tell us.

**We are evidence-based.** This families survey has helped us to gain qualitative feedback from our community about their experiences. We will use the findings from this report to guide us to achieve the best possible outcomes for those we serve.

**We are inclusive.** We recognise that cCMV affects everyone differently. We also recognise that people have different needs when being supported and how they wish to access support will vary considerably. By better understanding our community and their needs we can differentiate the support we offer to ensure an equitable access to the support and resources families need to improve their lives.

**We are accountable.** The remainder of this report provides the full findings and recommendations following our families survey. It serves as a transparent picture of our current position as we reflect, reset and embark on our ambitious new strategy.

### 3. Our survey

#### Approach

The survey ran for 16 days from Friday 28 June to Sunday 14 July 2024. Following launch on Facebook and Instagram, it received low levels of engagement over the first weekend, which is when we would normally expect to see one of the biggest spikes.

The charity ran a successful campaign for National CMV Awareness Month in June called CMV Warriors. A number of new families had engaged proactively with this campaign by sharing their stories. We sent direct emails to each of these families on Wednesday 3 July asking them to take part in the survey, which resulted in an increase in responses.

All other promotion of the survey had been conducted via social media. With a low response rate, we decided to use Mailchimp to send out a newsletter specifically about the survey. Historically the newsletter had been sent out twice a year, and an issue was overdue. Within the first day after sending the newsletter, we received 17 responses to the survey.

→ Immediately, this told us that:

- There is a very engaged group of families who do not appear to be on social media.
- Our focus to grow and engage our community has so far been on social media, and we need to be careful not to exclude a group of families who do not engage in this way.
- The newsletter frequency needs to be reviewed and increased to ensure that all our families are receiving our news.

#### Respondents

There were **46** responses to the survey in total. **35 (76%)** respondents said they were a direct carer of a baby or child affected by cCMV and **11 (24%)** said they were not.

**Table 1** shows the year the baby or child was diagnosed. As may be expected, there were more respondents in the more recent year ranges.

Year	Number of responses	% of valid responses
2020–2024	16	36%
2015–2019	12	27%
2010–2014	9	20%
2005–2009	5	11%
Longer ago	2	5%
<b>Total valid responses</b>	<b>44</b>	

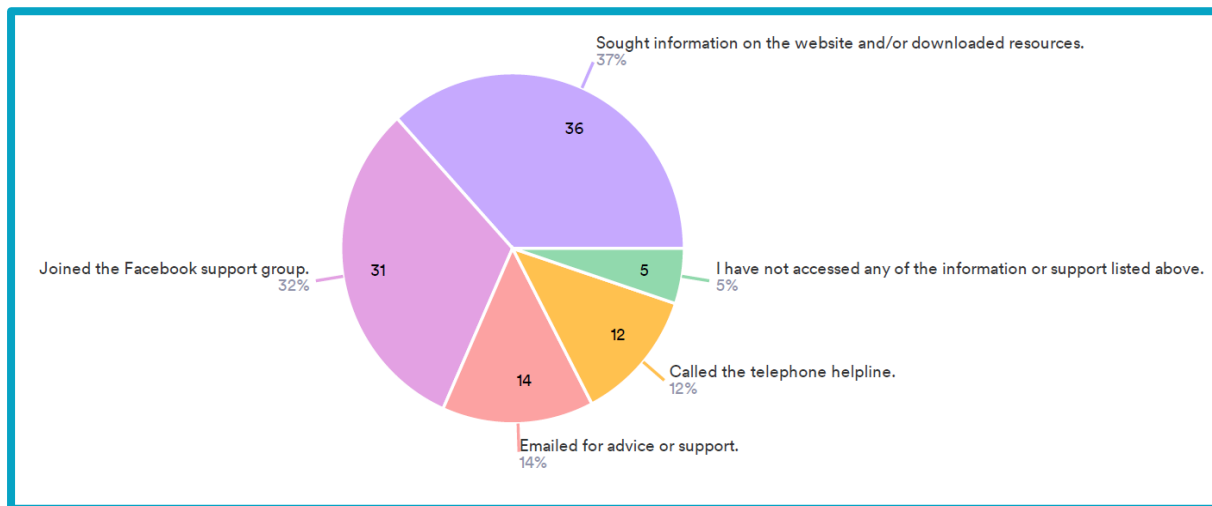
**Table 1.** Please tell us the year your baby or child was diagnosed

The majority of respondents (**83%; 34** out of **41** valid responses) said their baby or child was diagnosed at the age of 0 or 1. This includes some decimal answers given between 0 and 1, a negative number and one textual response of ‘pre-birth’. It is possible that others answering ‘0’ may have also had their baby’s diagnosis before birth.

The following sections relate to each question asked in the survey. Any quotes are used with permission from the respondent.

## What services have you accessed from CMV Action?

Respondents could choose multiple answers to this question, depending on the number of services they had accessed. In total, **98** responses were given, and **Chart 1** shows the distribution of these.



**Chart 1.** What services have you accessed from CMV Action?

The majority of respondents had accessed at least one service from CMV Action. Most commonly, this was using the website to find information or download resources (**36** responses; **37%**), followed by joining the Facebook support group (**31** responses; **32%**). There were **14** respondents who had emailed the charity for advice or support and **12** who had called the telephone helpline.

➔ These results show the importance of our online services in our current offer, so we need to make sure these are fit for purpose and responsive to community needs.

## What specific information and support has been the most helpful to you?

There were **23** textual responses to this question. Two key themes stood out:

- ➔ A community that shares, listens and supports
- ➔ Reliable resources and information, useful for both the family themselves and to raise awareness with others

**A community that shares, listens and supports** was important to people so that they didn't feel alone in their journey. They appreciated various types of engagement, but overwhelmingly they talked about support from other families. Below are some of the things people told us had been helpful:

*“Support for individuals, local groups”*

*“Support from other parents affected, social media awareness and other children experiencing the same things as my child”*

*“Reading other people’s experiences”*

*“Face-to-face conference about CMV”*

*“Setting up the original CMV support group”*

*“Bringing together families and sharing experiences and supporting each other going forward”*

*“In the early days, just to speak to someone who knew about CMV”*

*“Just knowing you’re not alone and everyone’s journeys are different”*

*“Seeing other people with similar stories and sharing our story has helped me cope with the long-term effects of CMV”*

*“The support of being able to talk to and read about other families in the same situation”*

*“The stories of other families impacted by CMV”*

**Reliable resources and information** were important for people to fill gaps in their own knowledge. Respondents had also found resources and information helpful in explaining the diagnosis to friends and family, as well as to use in raising awareness of CMV more generally. Below are some of the things people told us had been helpful:

*“Being able to find reliable information in one place”*

*“Factsheets”*

*“The very clear information about CMV both for ourselves and to give to others”*

*“What CMV is”*

*“I follow the Instagram and Facebook pages, which is reassuring and helps to raise awareness, which is what I want to do most”*

*“I’ve passed on the resource packs to local health professionals and childcare agencies to raise awareness. The factsheets are great for sharing statistics and quick information”*

*“The information on the Facebook page about CMV”*

*“Helpful graphics and other information to send to friends expecting babies has been useful to spread awareness”*

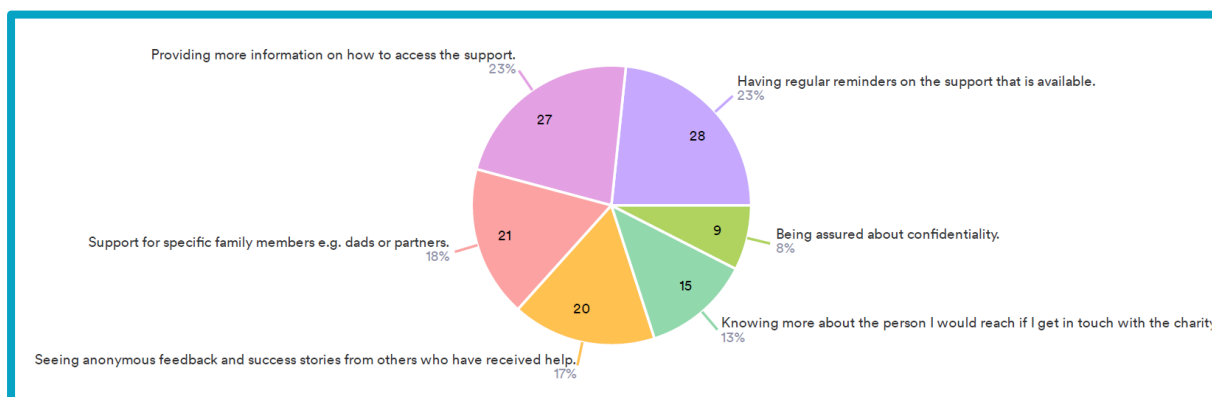
This question also drew out some negative points about the medical care families had received, in that people had turned to the charity for support and information when it was lacking in hospital:

*“The email service was invaluable after we were told our baby had tested positive for cCMV. We got a very detailed reply very quickly, whereas the hospital avoided talking to us about it”*

*“Stories of other children and how they are affected, as I see so many similarities with my child – issues that I think are related to CMV, but which professionals dispute are related – it helps when I see I’m not the only parent facing that issue”*

## What might encourage you or other families to contact us for help or support?

Respondents could choose multiple answers to this question. In total, **120** responses were given, which are broken down in **Chart 2** below.



**Chart 2.** What might encourage you or other families to contact us for help or support?

The top two answers (**28** and **27**, each comprising **23%** of the responses) were having regular reminders on the support that is available and providing more information on how to access the support. The next two most common responses were around support for specific family members (e.g. dads or partners) (**21**; **18%** of responses) and seeing anonymous feedback and success stories from others who have received help (**20**; **17%** of responses). A further **15** (**13%**) said it would be helpful to know more about the person they would reach if they were to get in touch with the charity, and **9** (**8%**) wanted to be reassured more about confidentiality.

➔ This ties in with what we had already realised from the newsletter communication about the survey. People don't necessarily know what support is available and how it could help them, so regular communication is key. As we expand our support offer, how we market ourselves and tell people about our services will be crucial.

## If we offered something new to help families, which FIVE services would be the most helpful?

There were **199** answers chosen under this question (not all of the **46** respondents selected five). The top five are shown in **Table 2** below.

Service	Number of responses	% of responses
Online information library for parents, carers and other family members	26	13%
Access to practical courses or advice, such as benefits advice, managing changes, etc	26	13%
Family days or social events	26	13%
Emotional health support (personalised sessions to meet your needs)	23	12%
Peer-to-peer support for parents and carers	17	9%

**Table 2.** If we offered something new to help families, which FIVE services would be the most helpful?

The top five responses show a range of different services, from general information to more personalised support. The community aspect is also deemed important, through both the social aspect and in terms of peer support.

### If we produced an online information library on cCMV, which FIVE topics would be the most helpful?

There were **204** answers chosen under this question (not all of the **46** respondents selected five). The top five are shown in **Table 3** below.

Resource	Number of responses	% of responses
My baby or child has cCMV – a parents’ guide	30	15%
What is cCMV?	29	14%
Services and organisations who can help our family	28	14%
Thinking about getting pregnant? Here’s what you need to know about cCMV	23	11%
A closer look at diagnosing and testing for cCMV	20	10%

**Table 3.** If we produced an online information library on cCMV, which FIVE topics would be the most helpful?

These responses give us some clear direction on where to start with our resources. Parents want to know the basics in a single guide, and then they want guidance on where to get support for their family. A notable number of people also placed importance on a pre-pregnancy guide. Bearing in mind that respondents are from our existing community who have the benefit of hindsight and experience, this is a clear indication that we can and should be raising awareness to inform people at a much earlier stage.

### How can we better support you and other families in our community?

There were **23** free-text responses to this question. Four key themes were running through responses:

- ➔ Raising awareness of cCMV before and during pregnancy, including better antenatal information and screening
- ➔ Better information for families post-diagnosis and throughout their journey
- ➔ Better information for healthcare professionals and others working with children
- ➔ More peer support opportunities



**Raising awareness of cCMV before and during pregnancy** was important to respondents, as many said they didn't know what cCMV was before they were diagnosed. **Prevention** and **screening** were raised as important factors in this, as well as general knowledge and information. Here are some of the things people told us:

*“CMV Action does good work – the information just needs to get out there more!”*

*“By campaigning for better testing during pregnancy”*

*“Helpful information in doctors’ surgeries to be aware of and help prevent CMV during pregnancy”*

*“For people to be more aware of what CMV is”*

*“Getting it screened while pregnant”*

*“Knowledge and awareness. I didn’t even know what CMV was until diagnosed”*

*“More information around testing and diagnosing”*

*“Giving more information to share on social media with what cCMV is”*

*“Greater lobbying in parliament for universal screening and awareness”*

*“Definitely sharing information to prevent the virus”*

A big part of improving awareness was around having **better information for healthcare professionals and others working with children**. Respondents often reported that their healthcare team didn't have the necessary information to give them the support and care they needed pre- or post-diagnosis. They also said that people like nursery workers should be more aware of cCMV. Here are some of the things people mentioned:

*“My biggest issue was that I hadn’t heard about the virus, nor had my health visitors, or various other healthcare professionals”*

*“Educating professionals about CMV so that I don’t have to do it every time we meet a new doctor”*

*“Raise more awareness – midwives, GP surgeries, hospital waiting rooms, general public awareness”*

*“Visit local nurseries and preschools to raise awareness among staff working in early years”*

*“Offer training for professionals who work with our children”*

*“A bigger push for antenatal professionals to know more so that it can be prevented earlier”*

Families wanted **better information post-diagnosis** in order to navigate the new territory they found themselves in, particularly with the lack of general awareness already noted. There were specific comments about different stages of the journey, including information following pre-birth diagnosis, resources to support the ongoing impact cCMV may have on a child as they grow, and information for the child themselves. Here are some of the things people told us:

*“I love the leaflet section and poster section online. I think more of them would be beneficial as they’re short and factual and aren’t overwhelming for new parents. They answer questions I hadn’t even thought of yet and make it a little easier explaining to friends and family what the diagnosis is, because I found that hard when I didn’t fully understand what it was myself”*

*“Knowing about the actual facts of CMV, especially cCMV, and how it affects the child day to day”*

*“We find it tricky to find answers later down the line – we got help initially but don’t feel we have a resource to go back to check if issues are ‘normal’ or cCMV related. Would be great to have this”*

*“More information when a child is diagnosed pre-birth on what to expect during labour and afterwards”*

*“Easy-to-understand info or a book for children who have been affected by the virus”*

Respondents mentioned a number of ways in which the support offer, particularly around **peer support**, could be improved:

*“I’ve never spoken to another parent whose child has cCMV – I wish I could do that. Talking to someone about how hard it has been and is to deal with the after-effects of this virus”*

*“A support group for parents and brothers and sisters”*

*“More support groups”*

*“Local support groups where possible”*

*“Peer support and emotional support following a diagnosis”*

*“Establish volunteer-run local branches across the UK which organise meetings where you can hear an expert speaker, network with other local parents and families to raise awareness and organise face-to-face meetings”*

*“Peer-to-peer support groups definitely”*

Some of the other thoughts people gave under this question were:

- Raising awareness within the transplant community, as CMV is a major risk within this group
- Practical advice around things such as applying to the council for extra waste collections due to medical needs
- Having a baby or child’s medical history all in one place so parents don’t have to start from scratch with different medical teams

### **Would you recommend our charity to someone in a similar situation?**

Of **42** responses to this question, **41** said ‘yes’. This gives us a positive base to build on as we review and develop our support offer. The one respondent who said ‘no’ didn’t provide any feedback under the free-text questions.

### **Any other feedback you would like to share with CMV Action?**

There were **9** free-text responses to this question, which followed the same themes as we have noted in the comments throughout, including:

- More publicity and social media content that families can share to help raise awareness
- Ongoing support and ‘checking in’ with families, not just immediately following diagnosis
- More information on testing and diagnosis
- More emotional support for parents and carers
- More short, simple factsheets/posters, including facts and figures

As a team, we were touched to also receive several messages of thanks in this section:

*“CMV Action is an amazing charity that I will always hold close to my heart. You helped us in our time of need when there was very little information and resources online about CMV. We received so much advice and support, it made such a difference. We are eternally grateful for CMV Action and all that you do!”*

*“Just want to thank you for being there for parents and the wider family. I am a grandparent of a child who was diagnosed with CMV when my daughter was roughly 19 weeks. You have been there for them, so thank you so much for being there and trying to get the message out about the condition”*

*“You are a light of hope”*

## 4. Our analysis and recommendations

Our families survey has told us some things we already knew and some that we didn't. Much of the feedback was positive and gives us lots to build on as we grow and improve. It will go on to inform the backbone of our plans as we take our high-level strategy to the next phase of detail, and we will continue to engage with families as this progresses.

Our key themes and recommendations from the survey are summarised below under our seven priority areas:

### → Support

- Support should be available in a number of different ways in order to reach each family in a way that works for them, e.g. online, local networks, telephone.
- We should use our communications frequently to let people know what support is on offer and how they can access it. This should be for the general population (e.g. leaflets in healthcare settings and online resources) and as a reminder to our existing community (e.g. social media groups and regular newsletter).

### → Information

- Information and resources should be available for every step of a family's journey: pre-pregnancy, during and post-diagnosis, and beyond.
- Information should be simple and factual for families to understand.
- Specific information should be provided for the children themselves and other family members.
- More general information about CMV and cCMV is needed across the wider population as part of our awareness-raising activity.

### → Training

- Training and information for healthcare professionals is of paramount importance so they can support families through diagnosis and support as they are going through the process.
- Other professionals working with babies and children need better access to training and information – in terms of preventing the virus from spreading in their settings and also understanding the needs of children with cCMV in their care.

**→ Research**

- We clearly have a wealth of knowledge, experience and enthusiasm in the families in our community. We must support them to get involved in research, engagement, campaigns and coproduction so that they are driving the developments in this field and in our charity.
- We should repeat our families survey at regular intervals; to monitor the impact of our new strategy and to ensure we are on the right track.

**→ Advocacy**

- We should continue to expand our awareness-raising activity with a view to influencing policymakers and wider public health campaigns, e.g. around prevention and screening. Our community should be a key part of this activity.

**→ Capability**

- Our strategy will help us to grow our support offer in light of what families have told us in this survey.
- Through this survey, families have trusted us by providing a rich collection of views, experiences and suggestions, and we will ensure that this informs our future plans and funding applications.

If you would like to discuss the survey or this report further, email [info@cmvaction.org.uk](mailto:info@cmvaction.org.uk)

To find out more about CMV Action, visit [www.cmvaction.org.uk](http://www.cmvaction.org.uk)