Coronavirus impact survey results

285 people responded to our coronavirus impact survey, which aimed to find out how the pandemic is affecting people impacted by meningitis. We wanted to hear about your experiences and find out more about how Meningitis Now can help.

We received responses from people of all ages, however, 80% were between the age of 25-65 years. Three quarters of people had either had an experience of meningitis themselves or had sadly lost a loved one as a result of meningitis. Whatever the outcome, the majority of people reported that their meningitis experience affected them in some way before the coronavirus (COVID-19) pandemic began, with as many as any 70% reporting a negative impact on their mental health and emotional wellbeing.

“Being separated from my major support networks is difficult”

“I’ve been spending more quality time with the family and planning ideas for our future”

Many of the concerns and worries that people told us about are things that most people are worried about during this difficult time. However, for people already affected by meningitis, these concerns are amplified or more complicated because they were already living with the impact of meningitis before the pandemic began - whether that is living with physical or mental health after-effects or coping with bereavement.

We identified six key themes:

- Relationships and feeling connected
- Employment and finances
- Mental health and emotional wellbeing
- COVID-19 concerns
- Education and childcare
- Access to services

Across most of these themes there were positives as well as negatives. People reported the positive impact that a slower pace of life had for their physical after-effects and mental health, enjoying more quality time with family and the reduced pressure from schooling or working from home.

“I’m constantly worrying about keeping my kids safe, especially my daughter. It takes me right back to her meningitis and I do get very scared and anxious”

“I’m less physically exhausted, and in less pain. I’ve found the opportunity to slow life down by working from home has had an excellent effect on my mental wellbeing”
90% reported that their meningitis experience affected them in some way before the coronavirus pandemic began.

55% of people said that they had found some things easier during the outbreak.

59% were feeling a little or a lot worse since the coronavirus outbreak.

34% felt no different.

7% were feeling a little or a lot better.

What have people found difficult?

53% - negative impact of COVID-19 on their mental health or emotional wellbeing

33% - uncertainty about work or finances

24% - accessing ongoing professional support

40% - accessing medical treatment

22% - homeschooling

48% - loss of their support network

32% - increased loneliness

53% - worrying about themselves or a family member contracting the virus

“I'm really concerned about my child not attending his usual therapies and hoping I'm doing a good enough job with him at home”

As a result of the survey we are:

• Adapting our services to deliver support and information to those that need it most. This includes developing more online support to help people keep connected, share experiences and feel less isolated.

• Providing emergency financial assistance for children and young people aged 0-25 years to support their education, learning and development.

• Creating and sharing more information about COVID-19 and meningitis that people can trust.

• Using the findings to inform our understanding, so that we can continue to deliver support for people with a range of meningitis experiences.

“Meningitis Now have been an incredible support - full of information and so helpful. Thank you, it's appreciated”