


Emotional support programmes for family and friends of people living with a kidney condition

Earlier this year, we ran an online survey about what family and friends of people living with a kidney condition wanted in an emotional support programme.

Here is a summary of what we learned!

Highlights

- 65 people took part in the survey
- 48% were likely to use an emotional support programme
- Participants were most interested in a programme available online (e.g. website), as a workbook, or in-person
- The programme should have information about lots of topics relevant to family and friends supporting someone living with a kidney condition.
 - For example: living with a kidney condition, support services, physical health, and diet
- 62% of participants wanted the programme to include support from a trained professional.
- Participants were most interested in support available in-person or via email from a trained professional working at a non-profit organisation



More details
on the next
pages

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Who took part?



Image from freepik.com

65 people
took part in the survey

Most participants were white women living in England who had been taking care of a male spouse with a kidney condition for 8 years

More than 80% were the only person providing support to the person living with a kidney condition

What did participants do to support their family member or friend living with a kidney condition?

Most participants helped with 8 different activities including:

- Emotional support
- Going to medical appointments
- Running errands
- Cleaning/gardening
- Cooking
- Helping with symptom management

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Juggling lots of responsibilities

In addition to supporting someone with a kidney condition...

- 51% of participants were working full- or part-time
- 38% of participants were providing care to someone else in addition to caring for someone living with a kidney condition

How were people feeling?

38%
were experiencing
symptoms of anxiety

58%
were experiencing
symptoms of
depression

46%
were experiencing
symptoms of stress



Emotional support programme preferences

What is an emotional support programme?

Emotional support programmes help people cope with different emotions like feeling low, sad, stressed, worried or anxious. These programmes use evidence-based techniques, for example based on cognitive behavioural therapy, that can be worked through over a few weeks.

48% of participants were likely to use an emotional support programme

How should emotional support programmes be delivered?

Participants were **most interested** in using a programme that was available:

- Online (e.g. website)
- As a workbook
- In-person



Participants were **least interested** in using a programme that was delivered by:

- Telephone calls
- Video-calls

What information should be in an emotional support programme?

There was interest in a lot of the topics we asked about.

Participants were most interested in information about...

- Living with a kidney condition
- Support services for family and friends of people living with a kidney condition
- Diet and physical health

Information in the programme should be available all the time

Emotional support programme preferences

Extra support

Emotional support programmes can be used by someone on their own, or a trained professional can provide some extra support and guidance to help people work through the programme.



62% of participants wanted to get some extra support with the programme

How should support be provided?

Participants were **most interested** in getting support...


- In-person
- Via a personal email

Participants were **least interested** in getting support via...

- Automated email/text messages
- Personal text message



41% of participants wanted to get support from a trained professional at a non-profit organisation



Only a small group of people took part in this survey. We know this means there are a lot of experiences and preferences we did not capture in this survey.

This project is just a first step towards developing an emotional support programme. We hope to engage many more people as we continue this work!



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WANT TO LEARN MORE?

Feel free to reach out if you have any questions or want to learn more about the work we are doing

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