

Collecting the experiences of young adults who have cared, or are currently caring for a parent with dementia

Facilitated by Charlotte England (Dulwich Centre Foundation)

Questions for young people caring (or who have been asked to care) for a parent with dementia

You may respond to any or all of these questions

1	What was it like for you when you found out about the dementia?
2	Have there been particular efforts you or others have done to try to make sense of the dementia?
3	How were you supported during this time, or how would you have liked to have been supported?
4	Have you had experiences of grief in response to your parent's dementia? If yes, how has this shown up in your life?
5	As a young person caring for a parent with dementia, how did you feel about the amount of information and understanding you had, of both dementia and being a carer, going into this experience?
6	Is there anything you want people who work in the medical and support fields to know about what would be helpful for young people moving through these systems?
7	What has been your experience of connecting with other young people in general (friends, family, communities) since the dementia and/or being a carer?
8	Have you found particular ways of connecting with people about the experience of caring for a parent as a young person?
9	Were/are there ways people in your life have been particularly helpful, supportive or understanding in how they've approached your relationship?
10	Have you accessed any support systems, organisations or programs designed to support young people caring for a parent? If yes, what was this experience like?

11	What has been your experience of responding to your parents dementia, whilst also caring (or making the decision to not be the carer) for them?
12	What has been your experience of being cared for yourself, whilst you cared for your parent? Have there been people, animals, places or things that have cared for you during this process?
13	Has gender (whether that is your relationship to gender or other people's perceptions of gender norms/roles) had an impact on your role as a carer? If yes, was there anything you found helpful in navigating this?
14	How do you feel about being a carer? If you were given a decision to become a carer, what did you consider when making this decision?
15	Has being a carer (or choosing not to) shaped the way you see yourself, or your identity? In what ways?
16	Have there been ways of navigating a relationship with a parent whose memory has changed that have been helpful for you?
17	Are there any memories that you are trying to hold onto, whether for your parent, yourself, or both of you?

Questions for young adults who have a fraught* relationship with the parent they are caring (or have been asked to care) for

* These questions are designed to speak to the added complexity of caring for a parent when there has been difficulties in the relationship. 'Fraught' can be replaced with whatever word(s) best describe your experience.

18	How do you feel about caring for (or being asked/expected to care for) somebody who you have a fraught* relationship with?
19	Have you found ways of acknowledging, honouring or validating the fraughtness* within the relationship, particularly when caring, especially if your parent has no memory of this? Are there ways that families, friends and community could help support this?
20	When talking to people about your parent's care, have there been ways that have been useful for you in communicating this fraughtness*? Are there any considerations that impact what/how much you share about this?