



Share your experiences 2024

In early 2024, we asked people to share their experiences of living with young onset dementia as part of a campaign to improve the experience of diagnosis and to raise awareness of young onset dementia. We asked our audience to answer three questions which were drafted in consultation with people affected by young onset dementia.

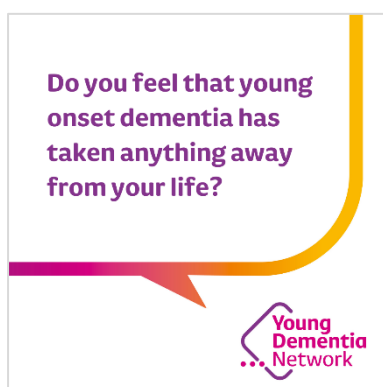
Over 200 people responded, of these:

- 32% were people living with young onset dementia
- 68% were family and friends*

*Family and friends include partners, parents, children and siblings

We have compiled the most common themes from the answers to our questions and a selection of quotes in this document.

Our first question asked if people felt young onset dementia had taken anything away from their lives.



Many of responses mentioned:

- the loss of the person with dementia as they once were
- changes to their abilities and occupations and how this altered how they felt about themselves
- hopes and expectations for the future have changed or been taken away
- a loss of independence, freedom and stability
- social interaction and relationships have changed

Some people told us that a diagnosis has given them a different perspective on life, allowing them to focus on new opportunities that the diagnosis has provided.



Losing your independence and having to rely on others to get through each day is something no one will understand until it's bestowed on them — **Person living with young onset dementia**



The person I married isn't there anymore, the man I live with now has a different personality. Conversation is gone. Empathy is gone. The sense of humour is gone — he used to have a great sense of humour — **Family member / friend**



It has left me more isolated — I don't think many people realise or understand that dementia can, and does, affect people in their 50's and sometimes younger. As such I think society is less tolerant of the struggles we face — **Person living with young onset dementia**



I look at things differently now. I found out who my real friends are and have made many more since — **Person living with young onset dementia**



Although I have gathered disabilities along the way, my dementia has also afforded me the opportunity to be involved as a dementia activist and so I have an occupation once again — **Person living with young onset dementia**

Has receiving a diagnosis brought any comfort or benefits to you or your family members and friends?



Our second question asked if receiving a young onset dementia diagnosis has brought any comfort or benefits. The responses were varied and often depended on the support the person had received following the diagnosis.

People expressed mixed emotions:

- it brought comfort to some, but many said that it did not
- it was a relief to be able to explain symptoms that they had been experiencing
- getting a diagnosis allowed them to move forward and plan ahead
- it allowed them to access support and services, but many told us there was a lack of support after diagnosis



Having a name of a disease that explained many of the difficult behaviours and life changes was very helpful and comforting — **Family member**



It came as relief to my family in the respect that we now knew what was happening and could start to make arrangements for the foreseeable future — **Person living with young onset dementia**



Once you have a 'label' on a condition you can find out more information. It opens up organisations such as yourselves and other dementia organisations — **Family member/friend**



Getting a diagnosis has allowed my family and I to get my affairs in order and now we can concentrate on living with dementia — **Person living with young onset dementia**

What are the young onset dementia symptoms that most significantly affect your daily life?



Our final question asked people to share which symptoms most significantly affect their daily life. Memory and other cognitive symptoms were mentioned, but not as frequently as the other symptoms listed below:

- issues carrying out daily living activities such as cooking and personal care
- communication difficulties such as problems with word finding, reading and writing
- mood and behavioural changes such as anxiety, low mood and depression, hallucinations and delusions, lack of empathy, disinhibition and denial as well as agitation, irritability including anger and sometimes aggression
- physical symptoms including mobility and coordination, sensory issues, sleep disturbances, incontinence, tiredness and fatigue, repetitive motor behaviours and headaches

Reduced independence caused by the impact of dementia symptoms was the most common issue mentioned by both the person with young onset dementia and family members. It led to a loss of freedom and impacted how they felt about themselves, their finances, their ability to work, to go out and socialise.



Speech problems are my main problem which affects my ability to converse with others — **Person living with young onset dementia**



Visual spatial difficulties are by far the most challenging. It took me a long time to recognise that he sees the world very differently to me — **Family member**



Aphasia — can't read or write easily and it usually takes me an hour to write a paragraph, I use AI to help me write — **Person living with young onset dementia**



I have to adapt all the time, and the most difficult thing is that nothing is visible from the outside — **Person living with young onset dementia**

People told us that it was not just the symptoms of dementia that impacted their lives, but the lack of awareness and understanding, particularly because of the invisibility of symptoms and the assumption of others that dementia occurs only in later life.

The Young Dementia Network would like to thank everyone who shared their experiences with us so openly and honestly.