

Talking Point chat room 25 February – Younger people with dementia
and their carers, families and friends.

SerenaS	Hello everyone :) Today's session is for younger people with dementia and their carers, families and friends. If you'd like to post a message, just type in the white box at the top and click 'ok' :)
SerenaS	Just to clarify - a younger person with dementia is normally considered someone who is diagnosed with dementia when they are under 65 years old.
Sue J	Hi everyone, what about the many other young people that are 'known or unknown about' but have undiagnosed dementia? I wonder if getting a diagnosis is particularly harder for young people precisely because of their age?
jilljay	Hi Serena. I have a daughter with dementia. She is 46
SerenaS	Hello Sue and Jill :)
jilljay	It took about six years to get her diagnosed.
Sue J	Hi Serena
jilljay	It is hard sue as there are many channels they have to go down before diagnosing it.
SerenaS	That's a very good point Sue - apparently many people are misdiagnosed with depression or have their concerns dismissed because they're not 'old enough' to have dementia. I understand you've had difficulties receiving a diagnosis - is that right?
Sue J	Hi Jilljay Six years is a long time it must have been very difficult - I am still trying after 5
Sue J	Yes Serena it is
SerenaS	Wow Jill that's such a long time. I wonder why it took that long. Was there something that happened that led to the diagnosis?
jilljay	My daughter also has severe learning disabilities too, but guess it is possibly as hard to diagnose even if the person hasn't got an L/D
jilljay	More and more L/D are getting dementia.
jilljay	Is it you or a relative who are waiting diagnosis Sue?
Sue J	I don't have LD so they think I'm fine! It is me Jilljay. It shows me that the tools used to identify and diagnose dementia are not adequate or refined enough
SerenaS	I'm sorry to hear that Jill. I think there are some studies at the moment looking at the links between people with down's syndrome and dementia.
Sue J	It must be hard for you to get support jilljay I would think but hope not
jilljay	I am so sorry Sue. Have you been to specialist hospital? My husband has dementia too but he is 71.
jilljay	I really do not think enough support is out there for anyone.
Sue J	I was at first rejected by specialist hospital despite my GP trying to rerefer me, I couldn't get there without support as I was too ill. I now have specialist psychiatrist but it is very slow as local mental health team think because I now have 'specialist support' why do I need their help
jilljay	My daughter actually started a GOLDD centre yesterday. Had no proper day care for nine etc years
jilljay	If only they listened to us Sue!!
SerenaS	That sounds very frustrating Sue :(
Sue J	What is a GOLDD centre?
jilljay	So what is actually happening to you now Sue?
Sue J	When my symptoms are worse it is very frustrating
jilljay	It is called that because it means Growing old with learning disabilities and dementia. GOLDD

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Sue J	I am still struggling to get support and refused to let them ignore me, again. Thankfully the psychiatrist will contact my GP to say I must have local support
jilljay	I don't know if GOLDD is country wide or just here in Brum.
Sue J	Can your daughter go often to the GOLDD centre
jilljay	Honestly as though we haven't enough to worry about. Now you have to fight to be recognised with a problem
jilljay	She is only going for one day a week at this moment of time but hope it will increase soon.
jilljay	What sort of support do you want sue?
SerenaS	It's good to hear that the psychiatrist is supportive Sue.
Sue J	Hopefully they will be tailored to meet your daughter's needs
Sue J	She is Serena thankfully and what a welcome relief
jilljay	Have they told you the type of dementia you have sue?
jilljay	They have always called my daughter's atypical dementia.
SerenaS	I hadn't heard of a GOLDD centre - it sounds like a great idea :)
jilljay	My husband has vascular dementia
Sue J	They haven't told me at all but I know something is very wrong
jilljay	There are only a few here Serena but think they are going to increase (I hope)
jilljay	So have you actually been diagnosed Sue?
Sue J	No it's taking a long time, that's my point I presented at GP over 5 years ago with horrendous symptoms
jilljay	That is why a chat room or board is so useful Serena. Learn a lot this way.
SerenaS	Hello to everyone taking a look at today's session, which is for younger people with dementia, their carers, families and friends. If you'd like to post a message just type in the white box at the top and click 'OK'
Sue J	I wouldn't have found TP if I hadn't have symptoms
Tony	Hi Serena just watching I don't fit the criteria today I'm almost 71 although I was 57 when I first got a diagnoses of Alzheimer's
SerenaS	That's very true Jill - I think the internet can bring people (and information) together across many miles :)
jilljay	Have you any suggestions for Sue Serena? It doesn't sound right at all that she is left in limbo not having any form of diagnosis?
Sue J	Nice to see you Tony
SerenaS	Hi Tony, you're welcome to join the discussion. The 'Younger' part normally refers to the diagnosis which was made before you were 65 :)
Grannie G	Good morning / afternoon everyone. I think you do fit the criteria Tony because you were diagnosed at a very young age.
Sue J	I am steps further forward but it's been a very tortuous route
jilljay	Hi tony. You are close to my age ,lol
SerenaS	Thanks Jill. I was wondering Sue, if you had any other support? It sounds like you have a helpful psychiatrist but I'm not sure about the GP. Are you in touch with your local Alzheimer's Society?
Sue J	Because of my symptoms I can no longer 'action' things quickly and I forget what/who I need to contact which is why I keep asking for help
Grannie G	Hi Sue. I think you've had a really tough time trying to get a diagnosis. It's as if you've had to fight for every tiny bit of recognition.
Sue J	The local AS society said they couldn't help because I don't have a diagnosis
jilljay	Can totally understand your worry Sue.

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Sue J	Sadly my GP changed and the current one doesn't know what to do with me!!!
jilljay	phone
Sue J	My psychiatrist will write to him which I hope will help, the practice is just not geared up to mental health problems of any sort]
SerenaS	I'm very sorry Sue.
Sue J	On my better days I just want/need to relax a bit as coping with the bad patches takes it out of me and I don't 'present' as someone with dementia but who does?
Tony	Ok thanks to every one Grannie G and Sue J, jilljay having a diagnoses obviously depending on age can sometimes can make thing worse in your daily life I battled for 15 years just retain my rights
Sue J	I am getting somewhere now though I think, hope if I dare
Sue J	I am aware of that Tony I think Drs are too which may explain their reticence to recognise or diagnose
jilljay	Back
jilljay	The new day centre phoned to see how my daughter was today.
Sue J	That was nice of them
Sue J	it's the little things that make the difference
Tony	The problem is one word fits all the word DEMENTIA unfortunately it doesn't fit all but you get stuck with it
jilljay	I thought that too. They had also been to her respite home and got more info.
Sue J	Spot on Tony - it's about needs
Sue J	that sounds really encouraging jilljay
jilljay	I have my fingers crossed ,lol
SerenaS	That's a very good point Tony. There's a long way to go before some attitudes are changed!
Sue J	I've just crossed mine for you too ;)
jilljay	In this climate of compensation I thinks Docs etc want to be extra careful of their diagnosis.
Tony	Serena you correct my dementia hasn't stopped me from living 90% a normal it the system of bureaucrats and their various forms
Sue J	It is difficult for Drs I think but there should be better multidisciplinary input within GP practices it shouldn't just be down to the GP
Sue J	A dementia nurse in every GP practice - now there's a goal
SerenaS	That's a great idea Sue!
Tony	yes jilljay you right I have on numerous occasion asked my GP & Consultant to leave the word dementia off the various forms obviously they won't because of the jobs worth issue
Sue J	Maybe AS could campaign for it?
SerenaS	We can certainly pass on the idea Sue :)
jilljay	Think I am in a different situation to you Sue and Tony. Have always had to care for my daughter and she is in the system.
SerenaS	We've got about ten minutes left everyone :)
Sue J	I think you are jilljay but must be very hard with your husband too having dementia
Tony	Serena in our area there is a nurse in the GP practice but I don't see her I have to go to the memory clinic
jilljay	I would like to chat to other parents in my position but rarely come across them, but must be lots out there.

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Sue J	Maybe through the GOLDD centre you may meet some?
jilljay	He isn't too bad at the moment Sue but will not try to help himself and I get very cross with him.
SerenaS	Jill - have you thought of starting a discussion on Talking Point - maybe in the 'younger people with dementia' section just to see if there are others on TP?
Grannie G	It's been good listening in to this chat. Younger people definitely have a tough time and it's a shame someone couldn't focus on their diagnosis and how difficult it is for people of working age to get the help they need.
jilljay	There is a carers group at this centre and am joining it if possible.
Sue J	It is sometimes very hard to help yourself with the horrendous symptoms believe me
jilljay	Think I have already done that at some point Serena. Think one answered but then nothing.
SerenaS	That's very true Sylvia - in order to receive proper support it seems a diagnosis is needed but in order to get a diagnosis, you need support.
Sue J	chicken and egg syndrome
SerenaS	Glad to hear there's a local group you could join Jill, and sorry to hear your thread didn't get a lot of response.
jilljay	I seem to be very caring to my daughter and am annoyed with my husband which isn't right of course.
Sue J	Hi Sylvia just realised hadn't said hello
Sue J	but understandable jilljay
Sue J	Thanks all
jilljay	Hi Sylvia. I didn't notice the names at the bottom until a minute or so ago.
jilljay	I wish a prof would sit him down and tell him to try to help himself!
SerenaS	Our session is coming to a close - before we go, I want to say a big thank you to everyone who participated and to all who popped in to take a look. :)
jilljay	I hope I am not being unreasonable with him
Sue J	People can respond better to a prof sometimes.
Sue J	Bye all look out for you on forum jilljay nice to meet you
jilljay	I do like this chat. Bit difficult with the format but expect I will get used to it.
Sue J	see you here again then
jilljay	Bye all thank you for your time patience and chat

Thanks for reading the transcript from our chat room session on 25 February.

Some resources for younger people with dementia:

[Younger people with dementia page on Alzheimer's Society website](#)

[Alzheimer's Society Factsheet about Younger people with dementia](#)

If you have questions about our chat room, please contact us by emailing talkingpoint@alzheimers.org.uk

You can view the chat room here: <http://forum.alzheimers.org.uk/chatroom.php>