Coping with a parent living with younger onset dementia – the experiences of the young people.

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This is my family
The Lost Tribe of Young People

Witnessing the disintegration of a parent with younger onset dementia, the impact on the young people.
Looking from the perspective of the young people.
Qualitative study

Researchers: Research Fellow Karen Hutchinson, Assoc. Professor Susan Kurrle, Assoc. Professor Chris Roberts.

Exploring the experiences and the needs of young people who have a parent with YOD.

Confidential semi structured interviews conducted with 10 young people in NSW to date.

Participants ages range from 10 to 33 years, 9 females and 1 male.

Some reflected on their experiences as a young person from as young as 8 years old.
Giving a voice

Some of the emerging themes from the research data:

- *Emotional trauma*
- Social stigma
- Social exclusion
Emotional trauma

The many emotions of the young people with a parent with younger onset dementia.
Negative emotions

- Anger
- Stress
- Frustration
- Sad
- Separation anxiety
- Grief and loss
- Hopelessness
- Lonely/isolated
- Wits end
- Not coping
- Fear
- Resentment
- Trapped
- Jaded
- A sense of unfairness
- Judged
- Shame
- Jealous
- Different
- Guilt
Underpinning emotions

Love, respect, dignity, protection and being a family.
Emotional Impact

“I stabbed myself in the thigh with the fork, just because I didn’t understand what was happening and I just was I guess just really gritting my teeth against freak out and depression and anxiety and dealing with the whole situation. I couldn’t quite comprehend what was happening. But I knew something was bad. Something was very bad.”
Mental Health issues

- Depression
- Anxiety
- Psychosis
- Obsessive Compulsive Disorder
- Self harm
- Alcohol
- Drugs
- Smoking
- Suicide ideation
Rough times

“I was always drinking to try and keep myself happy.”

I had “really bad depression and self harming.”

“I thought the pub was the greatest thing on earth when I turned 18. I was there a lot.”
Sleeping rough

“I’d just sleep in my car because I did not want to go home.”

“I have memories of spending two nights in the elevator…because it was the warmest place in the winter.”
I took off!

“..she (Auntie) said your mum would be better off if you weren’t here. Your just causing more trouble.”
“I felt terrible staying away.”
“The person is physically there but there’s also grief of losing someone……That person is not here anymore. But they are. But I cant reach them. But they’re right there….. is hard emotional circumstance for anyone to deal with…. especially a young person who really doesn’t have that emotional framework and faculties to kind of try to process it.”
“I’d always ask mum to get me a packet of cigarettes. Isn’t that terrible?....she hated smoking so much. With that pack of cigarettes I’d sell them to other kids and I’d make money….I’d buy a couple more cigarettes and then buy bread and milk and spaghetti and stuff-groceries.”
Being supported to be like other young people

“I think if I had more support then, then I would have been able to find the balance of being able to work and hang out and do other stuff, and maybe have respite or a carer support group or a counsellor. I just felt really alone.”
What do they need?

- Acknowledgement and understanding that we are impacted by younger onset dementia.
- To be like other young people.
- Support both practically and emotionally.
How can we meet their needs?

What present opportunities are there?
Opportunities for the Key Worker Role

Key workers can help to **discover** this lost tribe, **engage** with them and help to **connect** them to the appropriate support services.
At risk group!!

Anticipate before it transpires!!
If you don’t ASK you wont know!!
They don’t want sympathy they want support and understanding!

“I just felt they looked at me and go oh my God, this is above me. When you’re going to someone for help, you think I want help: I don’t want someone saying oh dear and just having these long awkward pauses, trying to think what could they say or looking like they are going to cry.”
Rise to the challenge

Help to **FIND** these young people so they are no longer the ‘lost tribe’, **ACKNOWLEDGE** their needs and **IMPLEMENT** appropriate support.
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Any questions??

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