

fFTD Seminar Monday 17 6 2024 Seminar Notes and Information

fFTD Gene Carriers Peer Support Group

Monthly on zoom facilitated by Nikki from the RDS Team. Eligible for RDS members who are confirmed gene carriers. It is an inspirational group with no judgement which explores different relationships members have and plenty of practical Tips ie: Having a family, Telling children-when/what do you tell them?, Care costs-now/future

Notes from the members experience:

Benefits of fFTD GC peer support group ?

Talking to others in same boat

Not a sad group, very inspiring and have a laugh at times

Safe and supportive environment

People that understand what you are going through

Sharing complex family set ups and conversations

Reasons for Testing?

Wanted certainty and gave clarity.

Test confirmation prompted to 'sort life' out

Some family not wanting to know

Some are 50/50

Some are 'head in the sand'

Sharing the news

Fear of judgement to tell others, some only told immediate family and close friends

No right answer

Research experiences

Participants often meet after research

Research updates shared from around the world.