childhood dementia INITIATIVE

Parent Knowledge Network Community Guidelines

Welcome

Our community guidelines help create the conditions for safe, respectful, and meaningful exchange, ensuring the expertise of lived experience remains at the centre, so that parent voices are heard, shared and documented as a resource for all families.

What this space is for

The Parent Knowledge Network exists to recognise and strengthen the expertise of parents in the childhood dementia community. It supports parents to share learnings, insights, and wisdom from lived experience, helps to reduce isolation, builds confidence, and makes it easier to find, share, and discuss practical, real-world knowledge.

Through regular sessions and shared resources, the network offers support for day-to-day challenges while building a growing library of insights for the wider Childhood Dementia community. The Parent Knowledge Network is a place to ask questions you can't easily ask elsewhere and to learn from families who truly understand your experience. It is not a therapy group or a place to receive professional medical advice, but a structured, peer-led space centred on lived experience and shared insight.

Our shared commitments

1. **We use respectful, inclusive language.** Speak from lived experience using "I" statements, avoid advice-giving, and respond to others with curiosity and care.
2. **We respect each other's expertise.** Every family brings valuable knowledge and insight. Experiences differ, and no one perspective represents all.

3. **We share with care in a recorded space.** Our sessions are recorded so every family can access the knowledge shared, whenever they need it. As you share, we ask you to speak from your own experience and keep others' stories private.

4. **We don't offer medical advice.** We share from our own experience, what has helped and what has not), without advising others what they should do clinically or medically.

5. **We make space for different experiences.** Families are at different stages, and needs may change over time. We avoid assumptions about others.

6. **We keep conversations focused.** Sessions have a clear purpose and intent. We will support purposeful sharing and all contribute to keeping the discussion on track.

7. **We support flexible participation.** Participation is optional and can take many forms. Listening, stepping back, or opting out is always okay.

8. **We record sessions to support access.** Sessions will be recorded to document and share knowledge as a resource for other families. You will be informed, and options are available to protect your identity and contributions if you wish.

Joining the session well (technical and privacy tips)

- Join from a quiet, private space where possible to support focus and help others feel comfortable sharing.

- Please mute your microphone when not speaking; the facilitator may mute participants if background noise impacts the group.

- If joining from a busy or public environment, use headphones, stay muted, and consider turning off your camera or using a blurred background.

- Headphones are strongly recommended, as conversations may be sensitive–please be mindful of who might overhear, including at home.

A Note on facilitation

Elham is the professional facilitator for the Parent Knowledge Network. Elham's role is to support the flow of sessions, participation, and knowledge exchange between parents. While bringing a background of professional experience in family support and care, their role in this process is to facilitate an inclusive, psychologically responsible space - and not to function as a therapist, teacher, or content expert.

This means supporting discussion through reflection and connection of ideas, rather than directing outcomes. As a result, some sessions may end with open questions or unfinished topics. As a peer-led process, feedback is welcomed.

Post session : Follow-up and aftercare

Recordings: Recordings and/or resources from each session will be made available to Parent Knowledge Network members. If you have any concerns about something you shared in a recorded session, please contact the Childhood Dementia Initiative team via services@childhooddementia.org to discuss.

Why are sessions recorded? Recordings support access for parents unable to attend live and help build a library of lived experience and practical insights for current and future families.

Seeking additional support for yourself : A knowledge exchange approach

The Parent Knowledge Network is a peer-led knowledge exchange space, not a therapy or crisis support group. While the primary purpose is to facilitate open and honest reflection from parents; share knowledge and insights with each other, some sessions may bring up thoughts or feelings that stay with you afterwards.

As peer participants, we remain the authority on our own experience, including what to share, what to hold, and what kind of support we may need in follow up. Sometimes, this might include sitting with discomfort that feels meaningful; at other times, it might be a sign that additional support would be helpful.

As a community-centred group, we encourage you to draw first on your own networks of support–trusted friends, family, or community members. If you feel your need for support goes beyond this (for any reason), the Childhood Dementia Initiative team can assist in connecting you with appropriate professional services. Our facilitator Elham is also experienced in supporting conversations like this, and can help guide you to further support as well.

Continuous improvement

The Parent Knowledge Network draws on established peer support models, is grounded in extensive consultation with families and is taking an innovative approach to parent knowledge exchange. We welcome your feedback at any time via services@childhooddementia.org and will ask for your feedback from time to time.