Experiences and Service Needs of Young People Living with a Parent with Young Onset Dementia

The Bouverie Centre, La Trobe University

Final Report - July 2025

Acknowledgment of Country

We would like to acknowledge the Wurundjeri People of the Kulin nation as the Traditional Owners/ Custodians of the land on which we work. We recognise their continuing connection to land, water, and community. We pay our respect to Elders past, present and the emerging leaders of the future.

Acknowledgment of Lived and Living Experience

The Bouverie Centre acknowledges people with lived and living experiences as workers, consumers, family members and carers, including those who have gone before us or are no longer with us. It is only by being informed and driven by the voices, collective experience, and wisdom of those with lived and living experience that we may create meaningful change.

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Executive Summary

- The Bouverie Centre at La Trobe University was funded by the Young People in Nursing Homes National Alliance (YPINHA) to conduct a set of two qualitative studies to understand and help address the needs of young people living with and potentially supporting a parent with Young Onset Dementia (YOD).

- The Bouverie Centre (Bouverie) is a practice-research organisation within the School of Psychology and Public Health, La Trobe University. Bouverie works with and studies families to address policy relevant questions that support the needs of Australian families and communities.

- Study 1 of the current project comprised a series of in-depth interviews with 10 young people about their current or recent experiences of living with and caring for a parent with YOD.

- Using the findings from Study 1, Study 2 then involved focus group interviews with practitioners working in the area to explore ideas about feasible improvements to service delivery and support systems to better meet the needs of dependent young people who are living with or caring for a parent with YOD.

- Practitioner experiences identified in Study 2 strongly resonated with the voices of young people from Study 1. Taken together, findings from both areas of enquiry offer rich insights about how best to understand and support the needs of young people and families facing parental YOD.

- This report provides a background and context for the project, including a desktop review of recent literature, then outlines the methodology, data analytic process and findings arising from each of the two studies mentioned above.

- We offer a series of recommendations arising from our understanding of the lived experiences of young people and the suggestions made by practitioners currently working to support the needs of families facing YOD in Australia.

- Findings are intended to bring about change in the sector to promote greater awareness of YOD, to uphold the voices and lived experiences of young people living with a parent with YOD, to support practitioners and services to understand and meet the needs of families facing YOD, and to ensure that funding is delivered thoughtfully and efficiently.

- Findings reported here will be also prepared for dissemination to the academic community via a manuscript to be co-authored by La Trobe University investigators and YPINHA partners.

Introduction

Background and context

A diagnosis of young-onset dementia (YOD) significantly impacts the lives of relatives of the affected individual, including children and young adult offspring, yet their experiences and needs often go unnoticed and unmet. Those living with YOD may still be part of the workforce, have children living at home and/or be caregiving for their own parents, and may experience symptoms including personality changes, memory loss, psychosis, lack of empathy, disinhibition, aggression, irritability, and apathy, which may have a harmful impact on children and young adult offspring's wellbeing. Little is known about the most effective ways to support young people living in this situation (Aslett et al., 2019).

Using Google Scholar, we conducted a desktop review to identify the past five years' evidence on young people's experience of YOD in one of their parents. We identified four articles that met our inclusion criteria:

i) published in an academic journal in the past five years [2020-2025];
ii) some or all study participants were aged 25 years or below;
iii) participants had a parent diagnosed with YOD; and
iv) the study explored the participants' lived experience of parental YOD.

These articles are summarised below and were published by: Aslett et al. (2019); Chirico et al. (2022); Cartwright et al. (2021); and Gelman and Rhames (2020). One of these articles was a qualitative systematic literature review of 15 studies (Cartwright et al., 2021), all meeting inclusion criteria ii-iv above, and published between 2009-2019.

Various recent studies have been published that explore children and young people's experience of parental dementia but do not focus specifically on *young onset dementia* (e.g., Chirico et al. (2021)) and that highlight the lived experience of YOD for patients and older caregivers but do not focus specifically on the experience of *young people* caring for a parent with YOD (e.g., Spreadbury and Kipps (2019)). Thus, studies that explore young people's experience of parental YOD are somewhat underrepresented in the broader literature but particularly important to addressing the policy relevant question of how best to support young people living in this situation.

Recent qualitative studies (Aslett et al., 2019, Chirico et al., 2022, Gelman and Rhames, 2020) speak to the significant impacts on young people of caring for and/or living with a parent with YOD. By way of interpretative phenomenological analysis of interviews with a small sample (*n*=5) of young adults, Aslett et al. (2019) explored the subjective lived experience of having a parent with YOD. The authors described five overarching themes in participants' experiences: relationship changes between young adults and their parent with YOD; adaptations to role changes since the parent's diagnosis; issues related to concern for the non-affected parent; types of informal and formal support for participants; and the various ways in which participants' own lives were affected by their parent's diagnosis. Findings were aligned with the stress-process model of caregiving for dementia, such that relational deprivation can negatively affect caregivers and family members. A key finding of this study was that of the anticipatory grief and ongoing sense of loss that young people experienced when their parent was diagnosed with YOD. Importantly, young people perceived their own life-course to be out of sync with those of their peers and felt uncertainty about their own future in the context of their parent's diagnosis. Central to participants' needs was for others to understand, identify and empathise with their situation.

Chirico et al. (2022) conducted interviews with family carers in Italy about their experiences of YOD and its impacts on their lives, family and social relationships, and support received. They report three key themes that describe participants' experiences: problems around the diagnosis; lack of post-diagnostic support; and the nature of living with YOD as a family. Children with caring responsibilities found it difficult to cope, and, as others have reported (e.g. Aslett et al. (2019)), found the experience of parental YOD to be at odds with expectations of their life stage. They experienced feelings of anticipatory grief and social isolation and described a pattern of role reversal in the parent-child relationship. A key finding here was the need for high-quality residential care for those with YOD as well as for those with older onset dementias.

Gelman and Rhames (2020) interviewed young people aged 16-20 years about their experience of parental YOD. They reported significant changes in family structure and roles, including a transition for children such that they assumed the roles of carers and earners. This study interviewed non-affected parents (all mothers) as well as children and reported that while mothers felt they were managing the bulk of the effects of YOD on the family to minimise the impact on their children, children reported significant effects on themselves. For example, children in YOD families felt a responsibility to care for both the parent with YOD as well as to protect the non-affected parent. These divergent experiences of YOD on family life suggest the importance of promoting awareness within affected families about how children often feel compelled to take on roles as carers, earners and reluctant partners in adult decision-making, and feel the weight of these roles (while muting their own lived experience).

In their qualitative systematic literature review of the lived experiences of individuals with a parent with YOD, Cartwright et al. (2021) provide a critical appraisal and thematic synthesis of the qualitative literature. This review included children both under and over the age of 18 years. Lived experiences of those affected by parental YOD varied widely, demonstrating the need for a person-centred approach to care (Cartwright et al., 2021). Across studies, the emotional impact of having a parent with YOD variously included feelings of resentment, embarrassment, envy of other children, anger, frustration, shame and distress (Cartwright et al., 2021). Feelings of loss and grief were common, as were coping difficulties and the experience of loneliness.

The recent synthesis of qualitative research in this space (Cartwright et al., 2021) suggests an overall lack of knowledge and understanding of YOD by professionals and the public. In line with this, many participants across studies included for review did not view themselves as a young carer, despite the significance of their role. Cartwright et al. (2021) describe a common uncertainty about where to access professional support, as dementia services are often aimed at older adults. This sits in the context of a lack of information and professional guidelines and recommendations in the

YOD arena. Across studies, children of parents with YOD made various suggestions in service of improving individual and family experiences: more investment in education, public knowledge, provision of information in school, accessible respite options for those with YOD, practical advice on how to handle specific behaviours, and simply having someone to talk to (Cartwright et al., 2021).

Caring responsibilities can impact young people's development and plans for the future (Cartwright et al., 2021, Chirico et al., 2022, Aslett et al., 2019) amidst impacts on the whole family including tension and conflict, changes in family roles, and financial struggles. Parental YOD in particular presents challenges related to the experience of anticipatory grief. Given the sensitive developmental stages that children, adolescents and young adults find themselves in, a holistic and systemic approach is needed to better understand the lived experiences and support needs of young people in families where a parent has YOD.

Recent attention to this area in Australia (i.e., work conducted in the *Joint Solutions Project*) has shed light on lived experience perspectives about gaps and barriers in services for those living with and caring for people with YOD (Loi et al., 2025). The Joint Solutions Project aimed to evaluate the gaps and barriers along the pathway of care in Australia from a range of stakeholder perspectives. Using a national questionnaire, this project gathered perspectives from those giving and receiving care for YOD. There was a high participation rate of those with lived experience. The results from this study suggested that certain aspects of service provision are indeed improving for people with YOD, but gaps remain in support systems, and importantly a majority of participants with lived experience reported difficulties accessing the National Disability Insurance Scheme (NDIS) (Loi et al., 2025).

Project aims

The current project aimed to add to the recent findings described above by gathering further, in-depth insights from 1) young people experiencing parental YOD and 2) practitioners working in the space to shed light on their lived experiences, to further inform an evidence-based improvement to the sector in Australia.

Project outline

The Bouverie Centre at La Trobe University conducted a set of two qualitative studies to address the needs of young people living with and potentially supporting a parent with YOD.

The project employed a two-stage approach to address its aims. Study 1 included in-depth interviews with young people (*n*=10, age range 14-35 years, with lived experience of parental YOD between 14-25 years of age) on their current or recent experiences of living with or caring for a parent with YOD.

Using the findings from Study 1 to report back to practitioners, Study 2 then involved two small focus group interviews with practitioners working in the area (*n*=5) to explore ideas on feasible improvements to service delivery and support systems to better meet the needs of dependent young people caring for a parent with YOD.

Study 1: Young People

What we did

Ethics

Ethics approval was provided by the La Trobe University Human Research Ethics Committee (HEC24523).

Participants and Recruitment

Participants (*n*=10) were young people with a parent with YOD. Participants were eligible for the study if aged between 14 and 35 years, with lived experience of parental YOD between 14 and 25 years. Participants were all Australian. Participants were recruited via the Young People in Nursing Homes National Alliance (YPINHA)'s existing research network including sites and institutions already working with families impacted by a relative's YOD. The recruitment flyer (see Appendix A) summarised the project and prompted interested parties to access the online Participant Information Statement and Consent Form. Where consent forms were completed, a La Trobe University research team member contacted the interested party to schedule an interview. For participants aged under 18 years (*n*=1), parental consent as well as participant assent was obtained.

Design

We conducted one-on-one semi-structured interviews via videoconferencing software of about 45 minutes in duration. Participants were offered the opportunity to have any questions answered prior to starting the interview and were informed that they could skip any questions or stop the interview at any point. See Appendix B for a copy of the interview guide.

Participants were reimbursed for their time with a $100 digital gift card, sent via email at the conclusion of the interview. Interviews were audio-recorded and transcribed for subsequent data analysis. To protect participants' identity, names and potential identifiers were removed from each interview transcript.

Analysis

We subjected the transcript data to a qualitative content analysis (Bengtsson, 2016; Hsieh & Shannon, 2005) to understand themes in the data. Using a predetermined coding system aligned with the interview structure, one independent coder extracted and coded transcript data using a standardised coding table. Codes and themes were reviewed by a second independent coder. Data analysis occurred across four stages: (a) decontextualisation (deconstruction of the transcript into meaning units); (b) recontextualisation (identification of codes); (c) categorisation (identification of themes); and (d) compilation (drawing of group-level conclusions and variations, with conferencing between coders and checking of the original text). Six key domains in findings were identified.

What we found

A summary of findings from each domain is presented below.

1: Family and Day-to-Day Life

- Young people described the challenges in balancing personal, work and study commitments with their caring responsibilities
- Many noted a changing structure and associated roles within the family unit
- Some described family cohesion, whilst others described an exacerbation of existing difficulties within the family unit
- Young people often maintained a sense of responsibility despite changes to their living situation e.g., when they moved out of the family home, or their parent moved into a care facility

2: Lived Experience of Living with/ Caring for a Parent with YOD

- Young people frequently described initial feelings of isolation and confusion following the diagnosis of YOD for their parent
- They described behaviour and mood changes in their parent as part of the condition
- Young people expressed experiences of disenfranchised and complicated grief
- They described a process of shifting the focus from their own experience and needs towards the needs of the family unit
- Young people reflected on the persistent stigma and lack of understanding surrounding the illness, in their immediate networks but also among health professionals and broader systems
- They reported an often prolonged and complex process towards formal YOD diagnosis
- Some young people noted positive elements of their lived experience e.g., a newfound closeness with the non-affected parent or with their siblings

3: Sibling Experiences and Relationships

- Young people described different ways of coping across siblings where various individual factors appeared to play a role such as temperament, age, gender, etc.
- For some, sibling relationships were strengthened and featured mutual support; for others, there was strain and present-day resentment
- Strong familial relationships and guidance from the non-affected parent appeared key for positive relational outcomes

4: What's Helped - Services and Providers

- Family assistance to navigate the service system (e.g., through a NDIS support coordinator or Local Area Coordinator) was described as helpful
- *Tailored* professional support for the parent with YOD was essential
    - These professionals needed to understand the specific care needs of the individual to provide appropriate support, or to advocate for the level of support needed
    - Continuity in care played a role, where some young people described certain support workers becoming 'part of the family'
    - The parent with YOD having a quality care team provided secondary benefit to the family unit, as they knew their parent was being provided with appropriate care and monitoring
- Formal supports (e.g., therapy, planned activities for the young person and parent) and informal supports (e.g., peer connections) were important to young people
- Practical supports (e.g., cleaning, gardening, respite, bursary) alleviated pressures from the family unit and consequently the young person
- Young people experienced their affected parent being engaged in activities that were enjoyable, meaningful and of interest to them as important; they felt this allowed their parent to experience quality of life particularly given the terminal nature of the illness and their own feelings of helplessness to assist in other ways

5: Gaps in Support

- Young people described a general lack of accessible services not only targeted towards themselves, but also for their parent with YOD and their non-affected parent e.g., due to the time/ location/ demographic of support group
- Supports were generally targeted towards older adults
- Young people identified a persistent gap in follow-up after the initial YOD diagnosis
    - Young people described them or their non-affected parent needing to actively navigate the service system whilst also managing their own grief and challenges
    - This role often fell on the young person in the absence of an alternate appropriate caregiver
- Some young people noted a pervasive gap in appropriate accommodation options for the parent with YOD

6: Support in an Ideal World

- Young people described the need for a roadmap for the family from the outset
    - They indicated the need for a framework to understand the illness, changes to expect, ways to give support to their parent with YOD and ways to get support for themselves and their family
    - They suggested the need for guidance regarding key transitions, and relevant services for example, NDIS, My Aged Care, and legal and financial matters
- Young people described a need for early, accessible and tailored support across the family's journey:
    - From someone who knows YOD, knows the family, and knows the system
    - Someone who can meet the family where they are at, including the current level of functioning of the parent with YOD
    - Somone who will not place the onus of proving the need on the young person
- Young people highlighted a need for peer support, and a space to step out of their carer role e.g., through respite or a supported space to enhance the parent-child relationship
- Young people described a need for more awareness of YOD generally—across universal services and their existing support networks
    - This was noteworthy in one young person being left out of important care decisions during a hospital admission, and in punitive measures i.e. being threatened to manage challenging behavioural presentations
- Young people urged for recognition of YOD as a palliative condition that requires specialised care, not just a generic disability approach that NDIS tends to adopt
- Early referral and intervention with the affected parent and family unit were identified as important to young people

Study 2: Practitioners

What we did

Ethics

Ethics approval was provided by the La Trobe University Human Research Ethics Committee (HEC24523).

Participants and Recruitment

Participants (*n*=5) were practitioners working with families where a parent has a young onset dementia. Participants were recruited via YPINHA's existing networks including sites and institutions already working with families impacted by a relative's YOD. The recruitment email (see Appendix C) summarised the project and prompted interested parties to access the online Participant Information Statement and Consent Form. Where consent forms were completed, a La Trobe University research team member contacted the interested practitioner to invite them to participate in one of two focus group interviews.

Design

We conducted two ~90-minute online focus group interviews with a total of five practitioners, all with current experience of working with families where a parent has a YOD diagnosis. Practitioner types included occupational therapists (*n*=2), a positive behaviour support practitioner, a family engagement counsellor and a speech pathologist/researcher. The first of the two focus group interviews included four practitioners. The second had been arranged to include two additional practitioners, but due to one non-attendance on the day, this included just one additional practitioner.

Participants were offered the opportunity to have any questions answered prior to starting the focus group interview and were informed that they could skip any questions or leave the interview at any point. See Appendix D for a copy of the focus group interview guide.

The structure of each focus group interview included a brief presentation of our findings from Study 1, followed by an opportunity for practitioners to reflect on the lived experiences of young person participants and then a series of questions covering practitioners' perceptions about best possible support of families and young people facing parental YOD.

Interviews were audio-recorded and transcribed for subsequent analysis. To protect participants' identities, names and potential identifiers were removed from each transcript.

Participation in the practitioner focus groups was voluntary (not reimbursed).

Analysis

As with Study 1, we subjected transcripts to a qualitative content analysis (Bengtsson, 2016; Hsieh & Shannon, 2005) to understand themes in the data. We derived several key themes in findings, discussed below. One independent coder analysed transcript data. Themes were reviewed by a second independent coder. Gaps and opportunities for change in the sector are summarised below.

What we found

Barriers to support seeking and engagement with services

- Service systems tend to be “fractured and unfriendly”
- There is a lack of recognition that support for young people is needed
  - By young people themselves
  - By service providers
  - By service systems
- Accessibility of information and support
  - Young people not knowing what supports exist and how to access them
  - Lack of time to seek out support (as a direct result of caring responsibilities)
  - Access limited by geographic location and funding
- Stigma surrounding YOD
- Limited involvement of young people in services from the outset (i.e., from diagnosis)

Gaps in support

- Lack of support tailored specifically to young people – there is better support available for very young children and older adults
- Lack of multi-tiered / multi-modal support frameworks offering practical, emotional, and educational support
- Lack of early, easily accessible, tailored, dementia-specific support
- Limited knowledge, training and education at multiple levels:
  - Immediate context that surrounds the young person (e.g., in schools)
  - Clinical settings (e.g., practitioner knowledge/awareness of the needs of the young person)
  - Services (e.g., funding providers, accommodation providers)

Opportunities for further support

- Involvement of young people early in the journey/diagnosis so they don’t start from a place of being ill-informed
- Tailored support across the family’s journey – consistency and quality of support and availability of services throughout the entire process (i.e., pre-diagnosis onwards)
- Building support on a foundation of trust and rapport with the family
- General education and more awareness raising to provide information, support and access to services for young people themselves, families, peers, teachers, and professionals – practitioners noted this could be done through:
  - Involvement with schools – educating peers, teachers, and young people
  - Leveraging phone/technology use of young people (including online forums and chat groups)
  - Social media – provision of accessible information
  - Support workers – fostering engagement and support seeking through strong relationships and trust between the young person and support workers working with the affected parent/family
  - Sharing of lived experience

- Improved accessibility of information – easing the load for young people through easily accessible, appropriate and tailored support
- Adopting a systemic, ecological approach to support – offering multi-modal support that taps into both formal and informal sources of support for young people
    - Focus on whole-of-family support and building rapport with the family unit before individualising support
    - Leveraging the power of peer support
    - Training for practitioners/relevant organisations – this can be facilitated by research
- Age-tiered support
- Leveraging existing and related programs/initiatives for young people
- Secondary benefit of appropriate carer and family support for the YOD affected family member

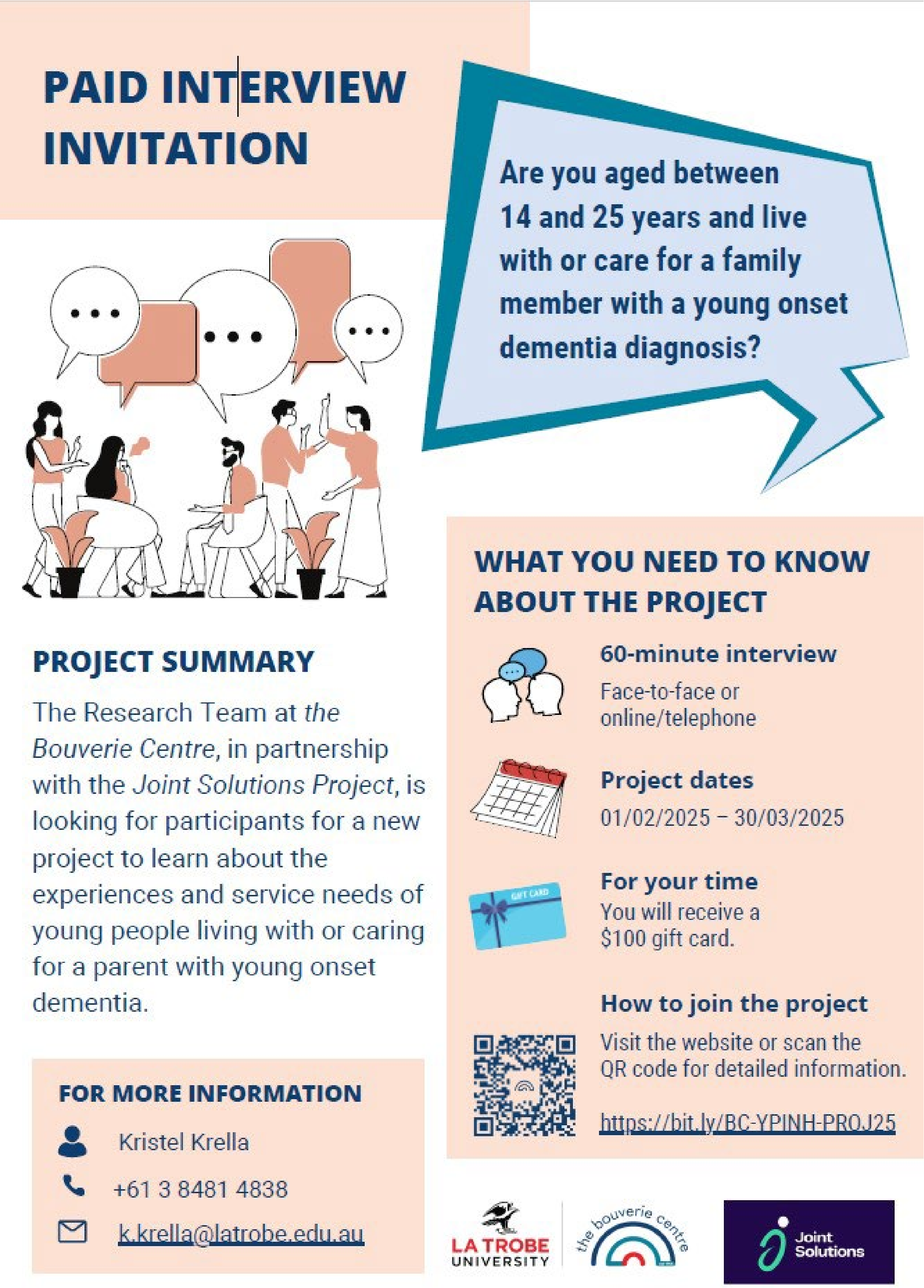
Future Planning and Recommendations: Where to from Here?

We found consistency across the lived experiences of young people (reported in Study 1) and the experiences of practitioners working clinically with families affected by YOD (reported in Study 2). Isolation, ambiguous grief and change in relational dynamics within the family unit (both positive and negative) were all indicated as important context for practitioners supporting the needs of young people experiencing parental YOD. In light of the perspectives provided by young people and practitioners, we offer the following recommendations:

- **General education and more awareness raising is needed** to provide information, support and access to services for young people, as well as family members, peers, teachers and professionals. This could occur through:
    - Education via the school setting
    - Leveraging phone or technology use among young people, including chat groups and online forums
    - Dissemination of accessible information via social media
    - Fostering engagement with support workers through strong relationships and trust between young people and support workers
- We need **improved accessibility of information** to ease the load for young people, who are often carrying significant burden and experiencing role reversed relationships in their family. This should be made available from the first point of contact with services.
- Echoing previous calls from the literature (Aslett et al., 2019), there is a significant need for young people experiencing parental YOD to have access to **meaningful peer support groups**. Young people find value in connecting with others who can understand, identify with and empathise with the lived experience of having a parent with YOD.
- **Young people should be involved early** in the family's journey with YOD, and age-tiered support would be beneficial.
- Current findings support previous calls for **high-quality residential care for younger residents** (Chirico et al., 2022).
- As YOD affects family members in distinct yet interrelated ways (Gelman and Rhames, 2020), a **family systems approach to models of care** can be useful. This would appreciate the experiences of the whole family and respond proactively yet flexibly to the shifting needs of children and parents. It is important to build rapport with the family unit before individualising support.
- **Training for practitioners and in organisations is needed** such that professionals working in the area can continuously build on their skills and knowledge.
- More broadly, **additional funding across the service sector** would be helpful to support the points made above.

Appendices

Appendix A: Recruitment Flyer for Study 1



PAID INTERVIEW INVITATION

Are you aged between 14 and 25 years and live with or care for a family member with a young onset dementia diagnosis?

PROJECT SUMMARY

The Research Team at *the Bouverie Centre*, in partnership with the *Joint Solutions Project*, is looking for participants for a new project to learn about the experiences and service needs of young people living with or caring for a parent with young onset dementia.

FOR MORE INFORMATION

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WHAT YOU NEED TO KNOW ABOUT THE PROJECT

60-minute interview

Face-to-face or online/telephone

Project dates

01/02/2025 – 30/03/2025

For your time

You will receive a $100 gift card.

How to join the project

Visit the website or scan the QR code for detailed information.

https://bit.ly/BC-YPINH-PROJ25

Appendix B: Interview Guide for Study 1

- Can you describe your family to me? What does your day-to-day life look like?
- In your own words, how would you describe the experience of living with or caring for a parent with young onset dementia?
- Do you have any siblings living with you in the family? How do you think living with or caring for a parent with young onset dementia has affected them? Has it affected your relationship with your sibling/s?
- Thinking back over your experience, what would you say has been helpful in managing this situation?
- Have there been any services or providers that made an important difference to you in handling that situation? Can you elaborate on what they have done and how this impacted you?
- Have there been areas you would have appreciated help with but could not find the right help at the right time?
- In an ideal world, what would support for you and your family look like?
- Is there anything I did not give you the opportunity to speak to, but you consider important for me to know in the context of this interview?

Appendix C: Recruitment Email for Study 2

Recruitment email sent to practitioners at funder partner sites working with families where a parent has a young onset dementia

Subject: Study invitation

Hello,

This is an invitation to participate in a Focus Group interview

Study title: Experiences and service needs of young people living with a parent with young onset dementia.

A team of researchers from the Bouverie Centre, La Trobe University, are seeking participants for a new project. The project aims to explore practitioner ideas on feasible improvements to service delivery and support systems to better meet the needs of dependent young people caring for a parent with YOD.

What would I be asked to do?

This would involve **being part of a 90-minute online focus group discussion with other practitioners working with families where a parent has a young onset dementia**.

- The **focus group** will occur as a small group discussion online with 4-6 other practitioners working in that area. This will take about 90 minutes and will be audio recorded.

If you are interested:

- Please get in touch with one of our team members by either clicking on the link below or giving us a call (03 8481 4800) or an email to Kristel Krella (k.krella@latrobe.edu.au).
- We will send you some more information about the study and ask you to provide your consent to be part of this research. Should you be under the age of 18 we also need a parent or guardian to sign the form we will. You will also be asked to tell us a bit about yourself and indicate your preferred interview time.

[link to contact page including PICF link]

If you have any questions, please just get in contact with us via phone (03 8481 4800) or respond to this email. Thank you for your consideration and we look forward to hearing from you.

The Bouverie Research Team

Appendix D: Focus Group Interview Guide for Study 2

Presentation of results from Study 1

- Do you have any immediate thoughts you want to share?

- Do these results reflect your own experiences? Do you think there is something missing that you experience in your work with families?

- What do you think would fill this gap?

- Are there any supports/services that you think can fill this gap but are currently underused?

- What do you think might help to encourage/promote the use of these underused supports/services?

- What do you think is getting in the way of helping families to manage this challenging situation

- Is there anything we did not give you the opportunity to speak to, but you consider important for us to know in the context of this discussion?

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