

**Research Report**

**Master of Research Project**

*A Trauma-Informed Pathway in Young Onset Dementia - An investigation of the potential for a trauma-informed pathway through dementia diagnosis for people under 65 years old*

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# Executive Summary

* This research aims to explore the diagnostic experience of individuals with young-onset dementia (YOD), their families, and the professionals involved, with a focus on identifying whether trauma-informed approaches were evident during the process.
* The project began in November 2023, with ethical approval from UWS granted in early 2024. NHS ethical approval, however, faced significant delays and was ultimately obtained in September 2024.
* Data collection began in September 2024, with interviews conducted with six participants (individuals with YOD and their carers).
* The final stage of data collection, involving four professionals involved in YOD diagnosis, will commence as soon as the extension of the ‘Letter of Access’ is approved.
* In addition to quarterly project updates, the following research dissemination activity has taken place:
* SDWG and NDCAN Meeting: PPIE Focus Group December 2023
* Dementia is a Multispecies World Workshop: Attendee February 2024
* Austrian Delegation: Attendee March 2024
* Carers’ Academy: Attendee March 2024
* Vlog: April 2024
* ASCPP Open Centre Meeting: Guest Speaker May 2024.
* UWS Research Festival: Poster Presentation June 2024.
* SDRC Conference: Guest Speaker June 2024
* REC Committee Panel Meeting: Presenter June 2024
* SDWG and NDCAN: Report August
* SDWG Meeting: Guest Speaker September 2024 (PPIE)
* The revised date of submission is April 2025. This is due to delays with ethical approval and access.
* The support from academic supervisors, colleagues and stakeholders has played a key part in the project's development.

# Background

Trauma-informed approaches recognise the risk of trauma from overwhelming psychological distress that often accompanies life-altering experiences. A dementia diagnosis, given its profound impact, places individuals and their families at risk of trauma throughout the diagnostic pathway (Scottish Government, 2023). The diagnostic process itself can introduce psychological risk (Sansoni et al., 2016), particularly in young-onset dementia (YOD), where accelerated cognitive decline and diagnostic delays (Loi et al., 2020; Kvello-Alme et al., 2021) often impede timely treatment, support, and care planning, intensifying distress for both individuals and families (Prince, Bryce & Ferri, 2011; Rasmussen & Langerman, 2019). Despite these risks, the criteria for a ‘quality’ diagnostic experience remain unclear, and whether trauma considerations are adequately integrated into this process is yet to be explored (Pickett et al., 2018).

# Research Aims and Objectives

In this study, we aimed to investigate the potential for a trauma-informed pathway through the diagnosis of dementia for people under 65 years of age.

## Objectives

* To understand the diagnostic experiences of people with young onset dementia and their families
* To explore how trauma-informed principles are applied in the diagnostic experience

# Methods

This study employs qualitative descriptive research (QDR) within a trauma-informed, family-centered framework, using data collected through semi-structured interviews.

A total of six participant interviews have taken place to date. This includes individuals with young-onset dementia (YOD), their carers, and caring dyads of people with YOD and their carers (shown in Figure 1).

Four professionals involved in diagnosing YOD have been identified and consented to participate; data collection for this group has not commenced. A non-substantial amendment has been submitted to NHS Ayrshire and Arran to extend the ‘Letter of Access,’ facilitating continued data collection from professionals.

Figure 1: Participant Data Collection

# Data Analysis and Results

Interview analysis is ongoing.

The interviews were audio-recorded and transcribed using Microsoft Word’s transcription feature. Data is being analysed through the five-stage Framework Analysis method by Ritchie & Spencer (1995), guided by the trauma-informed principles of safety, choice, collaboration, empowerment, and trustworthiness functioning as an ‘a priori’ conceptual framework.

Audio data was transcribed in compliance with the UWS Data Protection Code of Practice. All recordings, audio files, and transcriptions are securely stored on password-protected systems with authentication safeguards, in accordance with UWS data protection standards.

# Preliminary Findings

Early findings from the transcribed interviews that have taken place so far have found several themes emerging that illustrate what participants feel are critical components of effective support throughout their diagnosis experience.

These preliminary findings suggest that individuals highly value peer support, the flexibility to choose when and what type of support they receive, education about having dementia diagnosis and inclusive, detailed conversations with health professionals.

Preliminary themes are detailed below with in-depth discussion to follow in the final report and dissertation:

* Importance of Peer Support
* Choice – What Support and When
* Education – ‘Knowledge is Power’
* Included – In-depth discussions with Health Professionals about changes

# PPIE involvement

Patient and public involvement and engagement (PPIE) within research has been a priority throughout this project. Utilising the expertise of stakeholders is highly valued and has significantly shaped methodological considerations for data collection.

The researcher met with members of the Scottish Working Dementia Group and National Dementia Carers Action Network to discuss methodological approaches and potential risks. The advice from the members of the forum was as follows:

* Avoid personal questions to minimise potential distress.
* Open questions will allow the participant to lead the conversation. This will allow the participant to share what they feel comfortable with and ensure they feel safe.
* Ask participants to 'explain in your own words'.
* Do not assume anything about the participant such as where they are on the diagnostic pathway.
* Be mindful of the 'end point'. Once you feel you cannot go any further with the question then move on to the next.
* Use 'easy-to-understand' language.
* Presentation/seminar of findings to the group would be appreciated.
* Use the support of your supervisors as much as you can.
* When disseminating the project findings, ensure something is provided on word so members/participants can use the ‘read-aloud’ function.

# Timeline

* + - 1. **Expected timeline of project milestones**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Activity** | **November** | **December** | **January** | **February** | **March** | **April** |
|  |  |  |  |  |  |  |
| Extended IRAS Approval  |   |  |  |  |  |  |
| Interviews with Professionals |  |   |   |  |  |  |
| Ongoing Transcription of Interviews |   |   |   |   |  |  |
| Final Analysis |  |  |  |   |   |  |
| Write-Up |  |  |  |   |   |   |
| Final Review and Preparation for Submission |  |  |  |  |  |   |

# Student Reflective Log

The Master of Research project began in November 2023. As a new researcher, the project has allowed me to grow academically and professionally. I dedicate my academic and nursing career to people living with dementia and their families.

I continue to work closely with my supervisors, Dr Anna Jack-Waugh and Dr Eileen Harkess-Murphy, who share their knowledge and provide constructive feedback, supporting me in thinking critically about my work. We have continued to meet via Microsoft Teams every week with a review monthly. Our meetings are structured around any current deadlines, challenges, highlights, planning of events, feedback, and future planning.

Throughout the year, updates on the project are disseminated to stakeholders. This is a valuable part of the project, ensuring clear communication and updates are provided in various formats, including reports, vlogs, social media updates, and attending Microsoft Team meetings.

I have attended events that have allowed me to be part of academic and research environments, working with experienced researchers. Events include - Dementia in a Multispecies World workshop, Austria Delegation (Dementia) at UWS Lanarkshire, UAE visit at UWS Lanarkshire, Carers’ Academy, Alzheimer Scotland conference and travelled to Geneva to attend the Alzheimer Europe conference.

The original trajectory was intended to be submitted in November 2024. The ethical approval process took considerably longer than first anticipated. Ethical approval applications were submitted in January to the UWS Ethical Review Manager and NHS Integrated Research Application System (IRAS). Following various challenges, the REC Committee meeting in June 2024 and waiting for a ‘Letter of Access’, this was approved in September 2024. From here, the recruitment process was initiated.

A recruitment video was prepared and disseminated to potential participants with the support of various stakeholders. These included: 1. Individuals diagnosed with young onset dementia 2. Family/carers 3. Health professionals supporting those with young onset dementia. To date, I have recruited 6 participants.

Once recruitment is completed, I will analyse the data. I will identify themes throughout the data using the five trauma-informed principles (safety, choice, empowerment, collaboration and trustworthiness). This will directly address the aims and objectives of the project.

The revised date of submission is April 2025. This is due to delays with ethical approval, consideration of transcribing and analysis time and writing findings.

The support from academic supervisors, colleagues and stakeholders has played a key part in the project's development.