

Working in partnership to identify and support carers from point of diagnosis West Lothian Dementia Services

November 2022

West Lothian Dementia Post Diagnostic Support Services work in close collaboration with Carers of West Lothian (COWL) to ensure that carers are identified and supported from the point of diagnosis throughout the caring journey

In this impact story, we consider the factors making this initiative successful, its impact and learning.



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They (COWL) have a very good understanding of what it is to be a carer and the stresses involved in that. They talk directly to people and do so regularly- it's invaluable and allowed people to carry on caring.

Nurse, Post Diagnostic Support Service

Background

The West Lothian Older People's community mental health team provide one year of post diagnostic support for people living with dementia through the Post Diagnostic Support Service. Staff within the team recognised high levels of carer anxiety and highlighted the need for dedicated support. It was also recognised that a significant volume of information was provided at diagnosis, that could be overwhelming, and what was most valued by carers was the opportunity to talk about their concerns.

COWL were aware of the significant impact of dementia on carers, with one third of the 6,000 carers registered in West Lothian supporting someone living with dementia. A development worker from COWL was already providing support for carers during dementia assessment visits at St Johns hospital. The community mental health team and COWL agreed to work in partnership to increase support provided to carers of people with dementia within the community and introduced an approach to ensure early identification and referral.



Approach

A dedicated development worker based at COWL provides a specialist information and support service for carers of people living with dementia from point of diagnosis and throughout their caring journey.

- **Early identification and referral:** A Dementia Link worker from the post-diagnostic support service identifies the carer at the first home visit, following a patient's diagnosis of dementia. A formal referral is then made to the COWL development worker via an NHS email address.
- **Supporting mental health and wellbeing:** Following an initial conversation the development worker provides information about support and offers regular check in calls. As the caring role becomes more complex additional support can be offered e.g. condition specific training courses. Local peer support groups are offered to provide a place where carers can meet and share their experiences
- **Preparing for the future:** The development worker supports carers to prepare for the future regarding changing roles and relationships and understanding the support needs of the cared for person. A key element of this is to start the process of applying for Power of Attorney and ensuring that this is in place prior to the loss of mental capacity; a discounted legal service is available to reduce financial barriers and support carers with this process

Impact

The post-diagnostic support team refers an average of **150 carers** of people living with dementia to COWL each year. The impact of the COWL development worker has been highlighted through conversations with staff and carers.

The role has had a positive impact on:

- **carers**
- **staff**, and
- **the system.**



Impact on carers

- Support from someone who has a carer focus **enables carers to speak more openly and honestly about their challenges**, often sharing what they can't share with family, and has provided essential support to maintain and improve relationships.
- **Carers feel confident and safe to share information in peer support groups**, without feeling judged or guilty, as they are with people who understand what they are going through.



Impact on staff

- The post-diagnostic support service is a dedicated team of seven staff and supporting carers was previously a significant part of their workload. Staff are supported by knowing that the development worker is there and can see the difference this makes as **carers are supported by the right people in the right way.**
- Previously the team was introducing Power of Attorney conversations and downloading forms to share with carers. A formal service is now in place with support from solicitors, **saving staff time.**



Impact on systems

- Anecdotal evidence suggests that this support **reduces hospital admissions** as helps carers manage their caring role and prevents crisis by ensuring the need for support is identified and put in place earlier.
- By ensuring that Power of Attorney is in place the service impacts on the ability to make timely decisions about future care and can **reduce patients with dementia having a delayed discharge from hospital.**
- The development worker is now part of West Lothian's dementia working group for the HomeFirst programme and will be able **to influence the involvement of carers in hospital discharge pathways.**

Key enablers

- **Clear system for carer identification and referral**
The post-diagnostic support service have a consistent approach to identifying and referring carers that ensures this is done at first appointment. This process is enabled by the COWL development worker having an nhs.scot email address for sharing of confidential information
- **Working in collaboration**
The development worker role is trusted and valued by the wider health and social care dementia services, this includes hospital consultants and mental health practitioners. The development worker delivers the same key messages as the rest of the team ensuring consistency for carers. Through good relationship building, the development worker is also able to speak directly with hospital consultants when condition specific questions arise and additional information is required
- **Early intervention; a preventative approach**
Through identification of carers at diagnosis the development worker is able to build trusted relationships with carers early in their journey, prior to the caring role becoming more complex and problems arising. Having a trusted relationship enables the identification of carer needs and support being put in place.

Opportunities for improvement

- **Expansion of support to other carer groups**
The provision of carer support from point of diagnosis is working well with dementia services. There is an interest from COWL to develop closer working with primary care to expand this support to include other conditions.
- **Importance of Power of Attorney (POA)**
When POA is not in place for people without capacity there can be significant impact on the health service, particularly delayed discharges. Having earlier conversations with a wider range of carers, and ensuring power of attorney is in place would offer significant opportunities for improvement.

Further information

Find out more about Carers of West Lothian on their [webpages](#).

Find out more about the Older Peoples Community Mental Health Team West Lothian on their [webpages](#).

The Unpaid Carers Improvement Programme is part of Healthcare Improvement Scotland's Improvement Hub (ihub). Visit our webpages to read more about our improvement work, including further impact stories, on our [webpages](#).