

Enhancing Dementia Post Diagnostic Support through the use of Technology

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Background

In Scotland every person diagnosed with dementia is entitled to at least 1 year post diagnostic support.
Last year approximately 800 people were diagnosed with dementia in Lanarkshire. Information is delivered directly by link practitioners however this is not without restrictions and, due to an ageing population, there is increased demand for this service. Therefore people have fewer chances to plan ahead than they should have.

The aim was to address this by developing an online resource, with a locality focus; providing online access to post diagnostic information to those receiving a dementia diagnosis and those who support them.

Methodology

- Reviewed current research, polices and drivers
- Engaged with people with dementia and carers; collating evidence of information they wished/expected
- Engaged with all stakeholders providing Lanarkshire's Post Diagnostic Support (PDS); collating information provided
- Liaised with various organisations/groups (peer, community and carer supports); providing opportunities for input
- Steering group established; members from various agencies, person with dementia and carer
- Utilised Alzheimer Scotland 5 pillar of support Model (Scottish Government 2013)⁽¹⁾
- Users tested resource; providing feedback via questionnaire
- Piloted resource in 3 areas: Following diagnosis a leaflet provided detailing how to access.
- Measured outcomes; counting 'clicks' accessing site and a questionnaires designed in line with Dementia Post Diagnostic Quality Outcome Framework (2018)⁽²⁾.
- Sustainability assured by twice yearly reviews.

NHS Dementia Post Diagnosis Suppport **Planning** Supporting for future community decision making connections W **Understanding** the illness and For instructions on using this system click the 🌎 **Peer Support** managing symptoms **Planning for Future Care**

Aims & objectives

Everyone receiving a dementia diagnosis in Scotland is entitled to PDS. This empowers individuals to plan for the future (Scotland's National Dementia Strategy 2017-2020)⁽³⁾.

The aim was to improve access to post diagnostic support; ensuring that patients/carers are given information that assists them to plan throughout the illness.

Users are given a graphical "point and click" interface to seek the information they need from a trustworthy source, throughout their time with dementia and when they choose. Offering the information electronically has improved the number of options to upto-date, relevant information thereby enabling, connecting and empowering people with dementia and their carers (Scotland's Digital Health and Care Strategy 2018)⁽⁴⁾.

Face-to-face contact is still available but, for some, this approach can be preferable to repeated visits.

Results & outcomes

- Resource freely available to all in Lanarkshire; leaflet provided detailing how to access, following a diagnosis. Local libraries offer support to access.
 - Enhances current PDS offered without increasing workload.
- Information provided is what people with dementia/carers in Lanarkshire requested.
- Accessible information when required.
- Ensures access to validated information.
- Improves staff knowledge of dementia PDS and services within Lanarkshire.
- Provides continuity of information being provided.
- When dementia symptoms change, involved others can access advice; therefore potential reduction in required GP or CMHT support.

"Has a good 'one stop shop' feel to the site

also still be useful for future needs."

and wish we had been able to access this kind

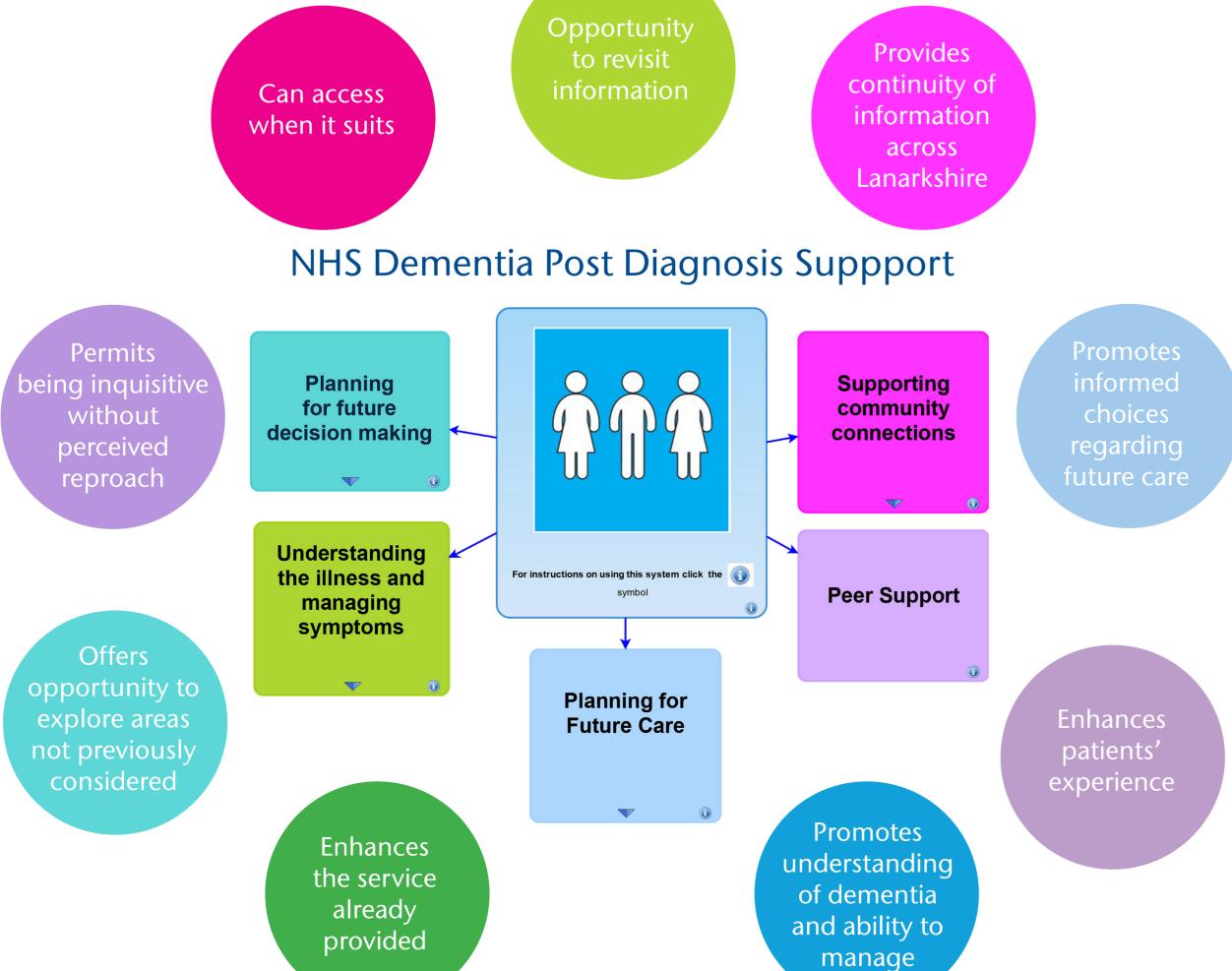
of resource when we started our journey. It will

DEMENTIA ONLINE POST DIAGNOSTIC SUPPORT

What's next?

- Monitor responses to using the system for enhanced on-going development and improvement.
- Up-scaling; the platform for this resource is freely accessible for all NHS Scotland health boards. The content could easily be adapted to incorporate local information. Therefore this resource could be provided by every health board in Scotland.

Benefits



Users Feedback

"As a carer for my wife who has dementia I found the information excellent and only wish that when my wife was diagnosed that I had the information on this website to hand. This website will be a great assistance to anyone diagnosed with dementia and also their carers."

"I found the website to be one of the most user friendly information sources I have seen. It is very well laid out in the flow chart style. This made navigation so much easier."

"All straight forward. Easy to use.
Accessed via emailed link but straight in.
Accessible from iPhone which was handy
and still readable on the smaller screen."

References

- (1) Scottish Government: Scotland's National Dementia Strategy 2013-2016, 2013
- (2) Healthcare Improvement Scotland: A Quality Improvement Framework for Dementia Post Diagnostic Support in Scotland, 2018
- 3) Scottish Government: Scotland's National Dementia Strategy 2017-2020, 2017
- (4) Scottish Government: Scotland's Digital Health and Care Strategy, 2018