There is a lot of stigma related to dementia, particularly when you are younger. Dementia never seems to be out of the headlines...but what I’ve learnt is that no two people are the same. I embrace every day. You can still do things, but in a different way, or you find a different approach. Yes the future is uncertain, but I suppose it’s always been that way, I’m just getting on with my life.

Younger person with dementia from Cardiff

Receiving a Diagnosis of Younger Onset Dementia.

The majority of people living locally will receive their diagnosis of dementia after having been assessed by the Cardiff Memory Team based at the University Hospital Llandough. Although it’s entirely possible that you will have received a diagnosis from a Clinician such as a Neurologist or Psychiatrist based within another local service.

The Clinician who has made the diagnosis of younger onset dementia has now referred you to the Younger Onset Dementia Service. This means that your care has been transferred from the diagnostic service to the Younger Onset Dementia Service, which will provide you with ongoing monitoring and support.

Welcome
To the Younger Onset Dementia Service.

The Younger Onset Dementia Service was launched in 2011 with the aim of developing and providing age appropriate support for anyone living in the Cardiff and Vale area diagnosed with dementia before the age of 65.

The Younger Onset Dementia Service is a multidisciplinary team comprised of professionals from a range of health disciplines including Nursing, Psychiatry, Psychology, Occupational Therapy, Physiotherapy, Dietetics, and Speech and Language Therapy. The Service also provides Family Support Workers and Dementia Care Advisors.

The Younger Onset Dementia Service works in close collaboration with voluntary sector Services such as the Alzheimer’s Society. Through joint working a wide network of support has been established.

What Happens Next?

Initially you will be invited to attend periodic outpatient clinic appointments at the University Hospital Llandough. You will receive an appointment letter inviting you to a review every six months.

The outpatient clinics are conducted by members of the Younger Onset Dementia Service. The purpose of the review is to ensure that you and your family receive an ongoing assessment of all your needs, through which we can ensure you experience continuity of care and responsive information, advice, support and treatment. Referral to other support services across social care and the voluntary sector can also be facilitated.

We do appreciate that attending such appointments can be a source of anxiety. Think of these meetings as a means of you and your family having an ongoing conversation with us about how best we can help you to live well and positively with dementia.
You are not alone

Prevalence Rates

There are estimated to be at least 42,325 younger people with dementia in the UK, or more than 5 per cent of all those with dementia. In Wales the figure is 2,200.

(Alzheimer’s Society Fact Sheet: 2016).

The Local Picture

The Dementia UK report (2014) indicates that across the Cardiff and Vale area there are likely to be 289 people under age 65 with a diagnosis of dementia.

These figures may well be considerable underestimates, and as public and professional awareness of dementia improves, the local network of support is growing.

Connecting you with a Network of Support

Through listening to people’s unique experiences and personal journeys we have been able to develop a range of services and support groups.

What we’ve learnt is that the best support often comes through meeting with others who understand through their own experience what it means to live positively and well following a dementia diagnosis.

Professionals from The Younger Onset Dementia Service facilitate a variety of sessions which provide opportunities to meet with other younger people living with a dementia diagnosis.

A Carers Social Group meets every month at a local public house / restaurant for coffee and mutual support. A monthly evening social / support group for anyone who has a parent or grandparent with younger onset dementia is also well attended.

A monthly Walking Group is very popular and sees younger people dementia, carers, family members etc enjoy each others company and share learning together.

These are a few examples of the support available. Ask a member of the Younger Onset Dementia Service for information. Together we can consider how best to connect you with this growing network of support. Or feel free to contact us—see the contact details on the front of this pamphlet.

The Younger Onset Dementia Service

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