National Young Onset Dementia Network

The National Young Onset Dementia Network is a movement of people living or working with young onset dementia committed to improving the lives of those affected.

Our purpose and mission is to

Improve the lives of people with young onset dementia and their families by harnessing passion, energy, experience and knowledge.

With this momentum, we will create effective connections and use these connections to exert a powerful influence over key areas that present a barrier to living fully.

By acting with strength and determination, we intend to bring about significant changes that will have a lasting benefit for people living with young onset dementia.

Our top priorities are

1. Raise awareness in public and promote understanding in all; including educate GPs and others in health and social care.
2. Clear route to timely diagnosis accompanied by a positive message and signposting for well-being.
3. Based on a clear statement of what is needed for people with young onset dementia, and their families including children, to live fully, a good level of support / information for all will be defined and we will seek ways implement over time.

Terminology

The term ‘living with’ encompasses both people ‘diagnosed with’ and family members or close others, i.e. people whose lives are ‘affected by’ young onset dementia.

Young onset dementia is currently understood to be dementia experienced in early/mid 60s and younger; it is dementia that is experienced in a stage of life that is different from the majority and because of the stage of life, dementia has a different impact on life. Using an arbitrary age is convenient but can present challenges.

Who is the Network for?

All people living with young onset dementia in the UK.
All people working with young onset dementia in the UK.

What is the Network?

Informal membership group with focus specifically on the impact of young onset dementia on everyday life.

Why set up the Network?
People living with young onset dementia report that there are obstacles to a life lived well and fully – key obstacles include

1. Insufficient, inequitable, inadequate services for people living with young onset dementia resulting in lives unfulfilled/ill-being

2. Lack of opportunity for people living and working with young onset dementia to learn from each other/support each other and to share experience and knowledge

3. Different needs/different impact on life/different stage of life – all of which need to be better understood by all areas that connect with people living with young onset dementia

The Network is determined to address those by drawing together people who really care, to agree what changes need to happen and then find effective ways to make them happen.

What will the Network do – our aims
To be a focal point for people living with and working with young onset dementia in the UK
To influence policies and improve services nationally
To be a conduit for the voice of people living with young onset dementia
To provide opportunities to share experience and knowledge, and learn from each other
To connect people living and working with young onset dementia

How does the Network work
The starting point of the Network is the steering group – this is the first stage of development. The intention is to work collaboratively and not to duplicate effort.

Role of steering group
The steering group role is primarily strategic.

Its membership is up to 20 – including people living with and people working with young onset dementia.

Key to being a steering group member is commitment and connections to other networks.

It is informed by topics and issues fed in people living with dementia

The steering group has set up work streams to focus on particular activities and these work streams benefit from the participation of other invited people.

During 2015 the steering group has been active, and we have put in place important resources to support the evolving Network. Over the course of 2016 the Network will be launched and membership encouraged widely.