

The development of early intervention for dementia in Worcestershire

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The Early Intervention In Dementia Team in Worcestershire has been operational for the last 18 months. The development was a long process and took four years from the original idea to the first patient being seen.

Reasons to change

Over the past 10 years there has been a change in type and volume of referrals to specialist services for people suspected of suffering from dementia. Before this time the majority of referrals were for people with established dementia, usually undiagnosed, and usually because of a pressing crisis in risk carer burden or disturbing symptoms. As awareness of dementia has steadily grown in the UK population there has been an increase in the number of people presenting relatively early in the illness process, often without significant need for care, who wish to know whether they are developing dementia. This change challenges service to deal with a greater volume of referrals at a time of demographic growth but also to deal with different needs at the assessment, especially making an accurate diagnosis in people with relatively subtle changes. It also offers an opportunity to work with patients at a time when they have the capacity to consent to the assessment process, the ability to take in the diagnosis and the opportunity to think about meaningful choices in their life, both now and in the future.

The development process

Developing a new way of working with people with dementia required the space for some creative thinking. A small group, initially professionals and later including voluntary and carer input, worked on the overall service model. Early involvement of commissioners was vital, especially at a time when Mental Health commissioning saw dementia as a low priority. The development process was already well under way when the National Dementia Strategy was published which added further impetus to the development of early intervention.

A deliberate decision was made to use the word "dementia" in the title of the service. This was supported by user and carer groups and was seen as an essential prerequisite for tackling the stigma. It also avoids inappropriate referrals of other people with memory difficulties that are not experiencing dementia.

The care pathway

The main purpose of the service is to provide a skilled diagnosis, shared well and then to help in the adjustment and to build family resilience. At the initiation of the service drug treatment was not recommended for mild dementia.

Referral

Referrals are taken directly from general practitioners and some are tertiary referrals from other clinicians in specialist services. We considered referral from nonclinical groups and self referral but as the service requires a physical health review, blood tests and a list of medication to be provided at referral this was not supported.

First contact

The first contact is by a nurse member of the team almost invariably in the patient's own home and in the presence of their family. The referral process and purpose of assessment is discussed, including the possibility of a diagnosis of dementia arising as a consequence. This gives an opportunity to show valid consent and willing cooperation with the assessment process and to find a patient's choice in whether they hear the diagnosis. 97% of service users opt to hear the diagnosis in the presence of their family, the remainder choosing not to be told, or to be told on their own. At the start of this service this first contact was aimed exclusively at preassessment counselling but we've increasingly found that many patients are keen to get on with the assessment process so where appropriate assessment history is taken at this point.

Second contact

This is the formal assessment appointment. Patients and their family are seen together and the history is completed. Cognitive testing, usually in the form of the Addenbrookes, is carried out. Unless the patient wishes their family to be present for reassurance cognitive assessment is carried out in private, giving an opportunity for families have an opportunity to speak and for carer well-being to be assessed. This appointment is held in a formal clinic setting, the majority in GP surgeries.

Imaging

Current NICE guidelines recommend that all patients being assessed for dementia receive neuro imaging. The majority patients receive a CT scan. MRI scans are also used.

The feedback appointment.

This appointment is exclusively for the discussion of the results of the assessment. Again, it is held in a formal clinic setting. The three components of the assessment, history, cognitive testing and imaging, are all reviewed with the attempt to building a coherent picture leading to a diagnosis. The patients are usually shown their CT scan in this process. The discussion then leads onto the diagnosis as an opportunity to have a brief discussion about the implications of this and answer any questions. Since the initiation of the service NICE guidance on drug treatment in dementia has changed so many patients at this point are now eligible to start drug treatment. Where appropriate this is commenced at the feedback interview.

The intervention.

Terry Pratchett recently said that at diagnosis people with dementia want to be shown on the path not shown the door. Most patients are seen approximately a fortnight after the diagnosis, this time by the nurse and usually in the patient's home. Common intervention involves emotional support for patient and family, advice and information, an offer to meet the local dementia advisor, an introduction to dementia cafes and also attendance at the psychoeducational days run by the team. Other more tailored interventions may include specific work by the team occupational therapist or clinical psychologist, referral to the admiral nursing service or referral to social services for a care package. This is a time when some people may wish to think of the future, discussing future care with families, taking out LPAs and even considering end of life wishes. Those who are driving are told of the need to tell the DVLA of the diagnosis and in car driving assessments are commonly recommended.

Leaving the service

Those patients who have been started on drug treatment will be reviewed again in clinic after three months to decide whether drug treatment has been beneficial. This usually marks the end of involvement with the early intervention team. Existing treatment guidance in Worcestershire allows GPs to take over prescribing and follow-up at this point. The majority of patients do not need ongoing involvement with specialists. Those who do are referred to the older adults CMHTs.

Challenges for now and the future

The team has benefited greatly from joint work with Worcestershire University Association for Dementia Studies, who have supported action learning sets and a service evaluation after the first year. This has helped guide ideas for the future, especially around the ongoing development of the intervention phase. The sheer volume of has been much greater than expected and has continued to rise steadily over the last 18 months, initially following the change in NICE treatment guidance and then following the national dementia awareness campaign. The work is both rewarding but also emotionally challenging for staff, with much greater emotional engagement in the adjustment process than previously experienced in a traditional old-age service. Worcestershire has never had a specialist working age dementia service so a large number of under 65's with dementia have been referred. The lack of suitable follow-on services has meant the younger people have tended to stay longer in the service.