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Clinical Psychology

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DAA Dementia
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Communicating a Diagnosis of Dementia

Sue Watts and FPOP colleagues

Alzheimer's
Society

Leading the
fight against
dementia

deep

The Dementia Engagement
and Empowerment Project



Communicating about a diagnosis

- **“Warning over a ‘desperate shortage’ of support following insensitive consultations”**

**Source: i, ‘the essential daily briefing’
from the Independent, 2nd July 2014,
reporting the Alzheimer’s Society Survey (2014).**



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Evidence

- Research, surveys and feedback from people with dementia and carers suggest that there is good and bad practice in sharing a diagnosis of dementia
- Research and surveys with professional staff suggest a mixture of reasons for this, including knowledge, training, skills and constraints due to work pressures and organisation of services

Some FPOP consultation comments:

- **Some positives:**

- *“The delivery wasn’t a problem as we’d built up to it”*

- *“The psychiatrist gave a rationale of how he came to his conclusion”*

- *“I got a long letter from my psychologist. It was very personal and human. This is what I needed”*

(FPOP Consultation, 2014)

Some FPOP consultation comments:

❑ **Some negatives:**

- ❑ *“I had a good relationship with my community psychiatric nurse, but they weren’t allowed to be there. I would have liked him to be part of the process”*
- ❑ *“You have an incurable brain disease...Didn’t even say sorry. I was in the room for two minutes”*
- ❑ *“Where I was let down was there was no immediate follow-up... ..It was like a vacuum, a cliff-edge”*

❑ *(FPOP Consultation, 2014)*

General issues

- More people are receiving a diagnosis of dementia and the process is quicker, but less attention has been paid to some other aspects of the process.
- Communicating about a dementia diagnosis is only one aspect of a communicating strategy which needs to span the entire process from referral through assessment and treatment.
- People have the right to choose whether or not they receive a diagnosis, some people make an informed choice 'not to know'
- Sharing a life-altering diagnosis is inevitably difficult for the person with dementia and the family, so communicating the diagnosis well is very important.
- Health care professionals (HCPs) often underestimate the difficulties people experience:

Issues (continued)

- Bad communication can be distressing and impact on well-being and engagement with services
- People may not express the extent of their distress during a consultation about the diagnosis
- Recall of any medical consultation is limited. Distress and dementia itself can increase this problem
- Diagnosis may be complex and involve periods of uncertainty which can be equally or more stressful than clear diagnosis.
- Some people may not be willing to take part in the process of dementia investigation. Consideration should also be given to the support, communication and information needs of the family and carers.

Table: Early Stage Dementia Care Pathway: Factors which increase the likelihood of successful diagnosis sharing

Point of referral (GP or other)	Pre-diagnostic counselling	Assessment by Memory Clinic or related service	Diagnosis-sharing session(s)	Post diagnostic treatment and support
Initial introduction and discussions about possible diagnoses	Pre-diagnostic counselling, exploring views and needs of person & family (see La Fontaine et al, 2014)	Effective explanation of investigations and findings during course of assessment (see Collerton & Domone, 2014)	Well planned and skilful session(s) covering diagnosis, taking account of perspective of person with dementia and family context	Follow-up support to develop understanding and engagement with treatment and management options (see Watts et al, 2014)

Some key aspects of good practice

- ❑ Have the clinical team understood the wishes & perspectives of the person with potential dementia diagnosis and his/her family?
- ❑ The skill with which assessment findings are integrated within a framework that is comprehensible and meaningful for the person
- ❑ Involvement of familiar staff from assessment process
- ❑ Sensitive use of language
- ❑ Attention to non-verbal communication
- ❑ Not too much information in one session
- ❑ Clarity in sharing results, rationale, name of diagnosis and any degree of uncertainty about diagnosis
- ❑ What the diagnosis means - symptoms, prognosis and treatment
- ❑ Acknowledge, monitor and manage distress
- ❑ Follow-up by the team, to check out and with the person and his/her family what they have understood from these discussions.

Strategies and resources:

- Increase awareness in service commissioners and providers
- Skills development, involving people with dementia and carers
- Checklists to help prompt good practice
- Clinical psychologists have specialist knowledge of communication, emotional and family processes. Can offer direct clinical work, clinical advice and supervision.
- Sharing a diagnosis is also difficult for staff. Skills training and supportive supervision are needed, to which clinical psychology can make an important contribution.
- Clinical psychologists have evaluation and research skills which can help services monitor the effectiveness of communication processes but also develop models to research and understand diagnosis sharing.

Summary

- There have been major improvements in many aspects of dementia investigation and diagnosis
 - Communication about diagnosis has received less attention
 - There is already a body of evidence which can help improve skills and practice
 - Service commissioning and design need to support a drive to improved, personalised clinical practice
 - Changes need to be informed by the experience and wishes of people with dementia and families/carers
- “ If you [HCP] communicate this wrong, and the person goes on a downward spiral, [the] resources are more to get them back to the surface. This cost would be greater to the individual and to society”*

Consultation Phase

- **Questions:**
 - Does this draft reflect people's concerns?
 - Are any key topics missing from the paper?
 - How can involvement of people with dementia and families/carers be integrated into service developments more effectively?
 - How should memory clinics be checking their practice?

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