

Early and Timely Intervention in Dementia: The FPOP Paper on Pre- Assessment Counselling

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Introduction

- **Research and policy advocate early diagnosis**
- **Many people want to know their diagnosis and to have the potential to live well with their diagnosis-difficult and emotional journey**
- **It is widely recognised that an important aspect of living well with a dementia involves choice and control for the individual and their family.**
- **On going process of assimilation and adjustment**

(Banerjee et al, 2009; DoH, 2009; Prince et al, 2011)



Research

- **Research has evidenced that people who are unprepared for a diagnosis of a dementia experience shock**
- **Pre-assessment discussions and informal feedback before diagnosis can reduce anxiety**
- **Assessment and feedback needs to be individualised (based on actual not perceived need)**
- **Unrealistic expectations = distress**

(Beattie et al, 2008; Bunn et al, 2012; Carpenter et al, 2008; Derksen et al, 2006; Karneili-Miller et al, 2007; Lecouturier et al, 2008; Manthorpe et al 2011; Robinson et al, 2011; Vernooij-Dassen et al; 2006; Wilkinson 2002)

Pre-assessment counselling facilitates choice, control and emotional wellbeing



Key Processes

- **Journey begins prior to involvement with services**
- **Using the word dementia, their understanding of what dementia is (past experiences etc) and allows for progressive disclosure**
- **Informed consent (understanding of referral and assessment/ outcomes and implications) is an on going process**

(Bunn et al, 2012; Chrisp et al, 2011, Cheston, 2013; Clare, 2002 in Moniz-Cook et al, 2006; Fisk et al, 2007; Karneili-Miller et al, 2007, Manthorpe et al, 2011; Moniz-Cook et al, 2006, Robinson et al 2011)



Key Processes

- **Roles and aims of service, discussing what assessment involves and talking about potential outcomes**
- **Establish ways of coping/ identify those at risk of greater distress or who are more vulnerable**
- **Retaining autonomy (including pace, timing, choice)...modelling the person being in control**

(Bunn et al, 2012; Chrisp et al, 2011, Cheston, 2013; Clare, 2002 in Moniz-Cook et al, 2006; Fisk et al, 2007; Karneili-Miller et al, 2007, Manthorpe et al, 2011; Moniz-Cook et al, 2006, Robinson et al 2011)



Challenges

Honesty, openness and hope

- Balancing honesty and hope.
- Using the word dementia is a challenge, but not being clear results in increased confusion/uncertainty
- Emphasis on strengths can balance focusing on difficulties, fosters realistic goals

(Bamford et al, 2004; Bunn et al, 2012; Cheston, 2013; Clare, 2002; Derksen et al, 2006; Harman & Clare, 2006; Karnieli-Miller et al, 2012; Lecouturier et al, 2008; Maguire, 2002; Manthorpe et al, 2011; Milne, 2010; Moniz-Cook et al, 2006; Robinson et al, 2011; Werner et al, 2013)



Challenges

Exploring expectations, fears and coping strategies

- Previous experiences and fears influence when people seek help.
- Individual and family's perspectives may differ from each other and may not be realistic. If expectations not met can increase frustrations and anxiety.
- Previous experience of loss can be important

(Bamford et al, 2004; Bunn et al, 2012; Cheston, 2013; Clare, 2002; Derksen et al, 2006; Harman & Clare, 2006; Karnieli-Miller et al, 2012; Lecouturier et al, 2008; Maguire, 2002; Manthorpe et al, 2011; Milne, 2010; Moniz-Cook et al, 2006; Robinson et al, 2011; Werner et al, 2013)

Facilitating informed consent

- Providing good quality information that is understood by person/family.
- Respecting people's decision to decline.
Supporting family members
- Making clear that people know how to come back to service, should they change their mind.
- Mental Capacity Act provides framework
- Informed consent is on-going

(Bamford et al, 2004; Bunn et al, 2012; Chrisp et al, 2012; Karnieli-Miller et al, 2007; MCA, 2005; Moniz-Cook, 2008; Werner et al, 2013; Williams et al, 2004)



Involvement of family or significant others

- GP referral may have been initiated by family member- difference of opinion regarding changes in mental skills
- Family may engage in ‘protective care giving’
- Listening, balancing and responding to competing needs, agendas, hopes and fears

(Bamford et al, 2004; Bunn et al, 2012; Crisp et al, 2012; Karnieli-Miller et al, 2007; MCA, 2005; Moniz-Cook, 2008; Werner et al, 2013; Williams et al, 2004)



Our Experiences

- **Positive and essential process (may be more than 1 appointment)**
- **People who chose not to engage with us are aware that they can be re-referred (and they do come back!)**
- **Importance of continuity of care (through assessment, diagnosis and post-diagnostic support)**
- **Access to/ close working with the whole MDT and other agencies – range of skills in the team (including administrators)**
- **Value of visual aids (map of the brain)**
- **Reduces “shock” and facilitates adjustment**

(Bunn et al, 2012; Derksen et al, 2006; Karnieli-Miller et al, 2012; Lecouturier et al, 2008; Manthorpe et al, 2011; Moniz-Cook et al, 2006; Robinson et al, 2011)

Comments

- *“it was quite clear as to what its objectives were and so, yes, so I entered into it without any fear at all”*
- *“you actually felt like somebody was listening and didn't think you were daft, or saying it was due to, to your medication and what have you, wasn't it?”*



Staff Comments

- *“Pre-diagnostic counselling was a new way of working for me, and I was initially sceptical, It is now for me the most rewarding aspect of the job”*

