Planning Ahead for People with Dementia
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INTRODUCTION
The pathway was designed to ensure that end of life issues were addressed in a timely fashion as part of the post diagnostic care for people with dementia. This was in keeping with the national standards for a dementia ICP.

METHODS
- Training and awareness raising workshops x 10
- Consultation with focus group of patients and carers
- Identified the common “what if” questions that people had
- Multidisciplinary working group produced an information booklet and planning ahead document.

FEEDBACK FROM TRAINING & CONSULTATION

Although this is a frightening thing to think about, it’s reassuring to now that I have the opportunity to say what I want.

It’s better to be prepared and it’s never too early to broach the subject of death and dying.

Good to have it on the agenda as it is very important to consider what the individual’s opinions are.

I have learned that this is an important issue and the more it is talked about, the less ‘taboo’ it will become.

Dementia Care Standard 29: There is advance care planning in relation to end of life care.
Criterion
29a The care record shows advance planning in relation to end of life care, which is:
• reviewed at least annually, and
• includes consideration of the preferred place of treatment if the condition worsens.

What if...I am asked about resuscitation?
What if...I am in pain?
What if...I have difficulties with eating and swallowing?
What if...antipsychotic medication is suggested?
What if...I need extra care and support at home?
What if...I need treatment with antibiotics?
What if...I have to go into hospital?
What if...I can no longer stay at home?

OUTCOMES - WHAT NOW?
- Integrated as a key component of the post diagnosis pathway
- Implemented region wide
- Funding has been granted from the Chief Scientists Office to undertake research into the impact of the planning ahead resources. This is a partnership project with Alzheimer Scotland and researchers from Edinburgh University

REFERENCES
- Standards for integrated care pathways for mental health, NHS Quality Improvement Scotland, December 2007