What are the experiences of people with dementia in employment?

Ruth Chaplin
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Rationale

• 17,000 people under 65 with a dementia in the United Kingdom.

• Many are still in work at point of developing symptoms and diagnosis.

• 1.4 million people over the age of 65 still in employment (Office of National Statistics 2012). With the removal of the statutory retirement age in 2012, this number and therefore the number of people developing a dementia while still in employment is set to rise.
Methodology

- Small scale qualitative study looking at “the lived experience” of people with dementia using Interpretive Phenomenological Analysis (IPA) methodology.
- Patients known to Older Adult Mental Health Services in Stockport.
- Used semi-structured interviews, audio taped.
- Analysed for emerging common themes, independently verified.
Inclusion Criteria

• A diagnosis of dementia
• Aware of diagnosis and able to discuss its consequences
• Able to give informed consent
• Be still in employment, either in work or on sickness leave
• Or have left employment within the last 12 months.
## Table Of Participants

<table>
<thead>
<tr>
<th>Occupation</th>
<th>Diagnosis</th>
<th>Age &amp; Gender</th>
<th>Employment Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing Assistant</td>
<td>Alzheimer's Disease</td>
<td>60 Male</td>
<td>Early retirement on grounds of ill health</td>
</tr>
<tr>
<td>HGV Driver</td>
<td>Vascular Dementia</td>
<td>60 Male</td>
<td>Dismissed. Now on ESA</td>
</tr>
<tr>
<td>School Meals Assistant</td>
<td>Alzheimer's Disease</td>
<td>58 Female</td>
<td>Dismissed, now on ESA</td>
</tr>
<tr>
<td>Businessman</td>
<td>Alzheimer's Disease</td>
<td>71 Male</td>
<td>Self employed, semi-retired</td>
</tr>
<tr>
<td>Engineer/Lecturer</td>
<td>Alzheimer's Disease</td>
<td>74 Male</td>
<td>Self employed, semi-retired</td>
</tr>
</tbody>
</table>
Main Findings

• A lack of openness and consultation between employers and the person with dementia.
• None of the participants were offered “reasonable adjustments” to their role under the Equality Act 2010 once a diagnosis was known.
• They accepted that they may have to leave work and wanted to “leave work well”.
• Overall, the 2 people who were self employed felt more in control of their situation.
Recommendations

• The provision of a clear advice leaflet regarding employment issues at the point of diagnosis.
• Training for staff in advising on employment issues.
• Joint working with Disability Employment Advisors and local agencies providing support.
• To publicise case studies of people with dementia who are successfully supported in work.
• Raising of awareness in Employers Organisations and Trade Unions.
Any Questions?