Effective monitoring & evaluation tools to assess the impact of emotional support services provided for carers

WEST CUMBRIA CARERS
CLARE EDWARDS & ABBEY WILLIAMSON
West Cumbria Carers (WCC) is a Registered Charity and Company Limited by Guarantee it was established in 1992.

WCC provides support to carers in the boroughs of Allerdale and Copeland in Cumbria.

WCC covers an area of 762 m² and a population of over 164,000.

2011 Census indicated that between 11-12% of the population considered themselves to be in a caring role. WCC are currently in contact with approx. 1,800 carers.

The area WCC covers is largely rural but has 6 wards/areas that appear in the top 10% most disadvantaged areas on England using the Index of Multiple Deprivation (IMD).

Initial funding for WCC Health Project Nov 2011 - June 2014 came from Cumbria Clinical Commissioning Group (CCG).

As a result of the Better Care Fund the funding from CCG and Cumbria Adult Social Care has been brought together in a single contract and a series of small scale grant funds.
Why services to support carers mental wellbeing?

A series of recent reports produced by national organisations; Carers UK and Carers Trust (formerly Princess Royal Trust for Carers) and Scottish organisation Carers Scotland have highlighted the huge numbers of unpaid carers who have significant mental health problems as a direct result of their caring role.

- Sick, tired and caring (Carers Scotland 2011) 86% of carers questioned reported that they suffered from stress, anxiety and depression.
- The State of Caring (Carers UK 2013) 92% of carers said that their mental health has been affected by caring.
- In Sickness and in Health (Carers Trust 2013) 87% of carers stated that caring had a negative impact on their mental health.
- The Cost of Caring (Carers UK 2011) 85% of carers who had been in debt (as a result of their caring role) also had suffered poor mental health.
What WCC provides

- Regular relaxation session (1 hour per month)
- Mindfulness Programme (8 week followed by 1 x monthly)
- Singing workshops (6 x monthly sessions)
- One to one counselling service (volunteer counsellors)
- Complimentary therapies (via ASC Carer Budgets)
Why is monitoring important?

• To ensure that the therapeutic interventions we provide to carers produce positive results for their mental well being

• To support carers to identify when therapeutic interventions have had a positive outcome

• To provide evidence to seek additional funding

• To provide quality feedback to existing funders

• To enable benchmarking against similar services
Improving access to Psychological Therapies (IAPT) - background

Launched in 2008 the Improving Access to Psychological Therapies (IAPT) programme is a large scale government initiative that aims to significantly increase the availability of NICE recommended psychological treatments for depression and anxiety disorders within NHS commissioned services in England.

The services have different names in each area:

• Cumbria & Northumberland – First Steps
• Manchester – Psychological Wellbeing Service
• East Lancashire – Healthy Minds
Our search for quality monitoring tools

- WCC designed evaluation and monitoring
- **The Warwick-Edinburgh Mental Well-being Scale**
- Affect Balance Scale (ABS) (Bradburn, 1969)
- Affectometer 2 (Affect 2) (Kammann and Flett, 1983)
- Depression-Happiness Scale (DHS) (McGreal and Joseph, 1993)
- Oxford Happiness Questionnaire (OHQ) (Hills and Argyle, 2002)
- Oxford Happiness Questionnaire - Short-Form (OHQ-SF) (Hills and Argyle, 2002)
- Psychological General Wellbeing Index (PGWBI) (Dupuy, 1984)
- **Short Depression-Happiness Scale (SDHS)** (Joseph et al, 2004)
- Wellbeing Questionnaire 12 (WBQ12) (Bradley, 1994; 2000)
National Institute of Clinical Excellence

All talking therapies delivered through IAPT services are approved through the National Institute for Health and Clinical Excellence (NICE)

NICE provide a full set of guidelines for the delivery of all services and recommend tools, methods and scales to use to assess

A good ‘read’ are a series of guides produced by Health Scotland [www.healthscotland.com/mental-health-publications.aspx](http://www.healthscotland.com/mental-health-publications.aspx) and in particular

‘Mental Health Improvement: Evidence and Practice. Guide 5: Selecting scales to assess mental wellbeing in adults’
## Patient Health Questionnaire for Depression (PHQ9)

Over the last 2 weeks how often have you been bothered by the following problems?

<table>
<thead>
<tr>
<th>Problem</th>
<th>Not at all</th>
<th>Several days</th>
<th>More than half the days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling nervous, anxious or on edge</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Not being able to stop or control worrying</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Worrying too much about different things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Trouble relaxing</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Being so restless that it is hard to sit still</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Becoming easily annoyed or irritable</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Feeling afraid as if something awful might happen</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

Column totals: \_ + \_ + \_ + \_ = Total Score \_

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

<table>
<thead>
<tr>
<th>Difficulty Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not difficult at all</td>
</tr>
<tr>
<td>Somewhat difficult</td>
</tr>
<tr>
<td>Very difficult</td>
</tr>
<tr>
<td>Extremely difficult</td>
</tr>
</tbody>
</table>

From the Primary Care Evaluation of Mental Disorders Patient Health Questionnaire (PRIME-MD PHQ). The PHQ was developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke and colleagues. For research information, contact Dr. Spitzer at rls8@columbia.edu. PRIME-MD® is a trademark of Pfizer Inc. Copyright© 1999 Pfizer Inc. All rights reserved. Reproduced with permission.
## Work & Social Adjustment Scale (W&SAS)

The Work & Social Adjustment Scale (W&SAS) assesses how an individual's mental health affects their work and social activities. It is adapted from Marks et al., 1986.

### Instructions

**Please rate each of the following questions on a 0 to 8 scale:**

0 indicates no impairment at all and 8 indicates severe impairment.

### Questions

1. **Because of the way I feel, my ability to work is impaired**
   - 0: Not at all impaired
   - 8: Severely impaired

2. **Because of the way I feel, my home management (cleaning, tidying, shopping, cooking, looking after home or children, paying bills) is impaired**
   - 0: Not at all impaired
   - 8: Severely impaired

3. **Because of the way I feel, my social leisure activities involving other people (such as parties, outings, visits, dating, home entertainment, cinema) are impaired**
   - 0: Not at all impaired
   - 8: Severely impaired

4. **Because of the way I feel, my private leisure activities done alone (such as reading, watching TV, gardening, craft work, walking, sewing) are impaired**
   - 0: Not at all impaired
   - 8: Severely impaired

5. **Because of the way I feel, my ability to form and maintain close relationships with others, including those I live with is impaired**
   - 0: Not at all impaired
   - 8: Severely impaired

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Work and Social Adjustment Scale
Adapted from Marks et al., 1986

Please rate each of the following questions on a 0 to 8 scale:

0 indicates no impairment at all and 8 indicates severe impairment.

1) Because of the way I feel, my ability to work is impaired
   
<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all impaired</td>
<td>Severely impaired</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2) Because of the way I feel, my home management (cleaning, tidying, shopping, cooking, looking after home or children, paying bills) is impaired

3) Because of the way I feel, my social leisure activities involving other people (such as parties, outings, visits, dating, home entertainment, cinema) are impaired

4) Because of the way I feel, my private leisure activities done alone (such as reading, watching TV, gardening, craft work, walking, sewing) are impaired

5) Because of the way I feel, my ability to form and maintain close relationships with others, including those I live with is impaired

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Name: 
Date: 

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Adapted from Marks et al., 1986

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Not at all impaired
Severely impaired
Patient Health Questionnaire for Anxiety (GAD7)

<table>
<thead>
<tr>
<th>Problem</th>
<th>Not at all</th>
<th>Several days</th>
<th>More than half the days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Little interest or pleasure in doing things</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling down, depressed, or hopeless</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trouble falling or staying asleep, or sleeping too much.</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>Feeling tired or having little energy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor appetite or overeating</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling bad about yourself — or that you are a failure — or have let yourself or your family down</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trouble concentrating on things, such as reading the newspaper or watching television</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thoughts that you would be better off dead or of hurting yourself in some way</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Pre & Post Questionnaire pilot

Our therapeutic interventions were evaluated in a fairly informal manner using specifically designed evaluation forms and questionnaires.

Analysis of these evaluations and questionnaires suggested that the interventions were producing some very positive responses and that carers mental health was showing significant signs of improvement as a result.

It was felt that it was important to look for a more formal context in which to develop benchmarking and evaluation processes to track and record the positive impact of the interventions.

We decided to pilot a more formal process with a small group of carers that had accessed one or more of the following:

- One to one counselling with a trained counsellor
- One hour relaxation and meditation technique sessions
- Eight week programme of two hour Mindfulness and Therapeutic Exercise session
- One to one therapy sessions including; massage, reflexology, Indian head massage etc

Initially an availability letter was sent to thirteen carers who had accessed one or more of the interventions.

Carers were asked to indicate their willingness to be involved in the study and their availability for telephone interviews. Those who indicated a willingness to be involved were contacted at a time convenient to them between December 2013 and February 2014. Of the thirteen carers approached, nine responded, all of whom completed the questionnaires in full.

The questionnaires were delivered via the telephone and participants were given the opportunity to expand on or refuse to answer any of the questions which were of a particularly sensitive nature.
## Recording responses

<table>
<thead>
<tr>
<th>Carer Surname</th>
<th>Carer First Name</th>
<th>Date of Birth</th>
<th>Sex</th>
<th>District</th>
<th>Relationship to Cared For</th>
<th>Condition of Cared For</th>
<th>Treatment Received</th>
<th>Anxiety (GAD Score)</th>
<th>Anxiety (GAD Rating)</th>
<th>Depression (PHQ9 Score)</th>
<th>Depression (PHQ9 Rating)</th>
<th>Work and Social Adjustment Score</th>
<th>Work and Social Adjustment Rating</th>
<th>Impact on Caring Score (0=Low Impact, 8=Severe Impact)</th>
<th>Impact on Caring Percentage Change (%)</th>
<th>Pre Treatment Assessment</th>
<th>Post Treatment Assessment</th>
<th>Progression</th>
</tr>
</thead>
<tbody>
<tr>
<td>Example</td>
<td>Example</td>
<td>11/11/2011</td>
<td>Male</td>
<td>Allerdale</td>
<td>Spouse</td>
<td>Mental Health</td>
<td>Mindfulness</td>
<td>19</td>
<td>Severe</td>
<td>24</td>
<td>Severe</td>
<td>33</td>
<td>Moderate to Severe Psychopathology</td>
<td>7</td>
<td>Mild</td>
<td>9</td>
<td>Normal</td>
<td>3</td>
</tr>
<tr>
<td>Example</td>
<td>Example</td>
<td>02/01/1944</td>
<td>Female</td>
<td>Copeland</td>
<td>Spouse</td>
<td>Mental Health</td>
<td>Mindfulness</td>
<td>19</td>
<td>Severe</td>
<td>25</td>
<td>Severe</td>
<td>36</td>
<td>Moderate to Severe Psychopathology</td>
<td>7</td>
<td>Mild</td>
<td>3</td>
<td>None</td>
<td>5</td>
</tr>
</tbody>
</table>

Note: A Minus Score indicates a positive change. In total of improvements has decreased by no value.
The Patient Health Questionnaire for Depression (PHQ9), Patient Health Questionnaire for Anxiety (GAD7) and the Work and Social Adjustment Scale (W&SAS) were trialled on a small sample of nine carers. The findings were:

• Pre therapeutic intervention resulted in an average depression score of 15.3 (moderately severe). The average score for depression fell considerably after carers accessed therapies dropping to just 6.2 (mild).

• The overall average score for anxiety amongst the carers pre intervention was 16.1 which would indicate severe anxiety. After accessing the services provided by West Cumbria Carers the average score fell to a considerably lower average of 7.3 which reduces harmful severe bouts of anxiety to a more manageable moderate level of anxiety.

• Work and Social Adjustment questionnaire scores also changed in relation to pre and post therapeutic access with average scores dropping from 25.8 (moderately severe social impairment) to 15.5 (less severe social impairment)

This Pilot Study provides robust evidence that the use of PHQ9, GAD7 and Work and Social Adjustment Scale provides a clear, useful and accessible process for our organisation to assess the success of the following interventions with carers

• One to one counselling with a trained counsellor

• One hour relaxation and meditation technique sessions

• Eight week programme of two hour Mindfulness and Therapeutic Exercise session

• One to one therapy sessions including; massage, reflexology, Indian head massage etc
Current implementation

Having piloted the use of pre & post questionnaires we have now rolled out the process since July 2014 to cover all carers using the following:

- One to one counselling with a trained counsellor (*carers complete pre before 1st sessions and post at last session*)
- One hour relaxation and meditation technique sessions (*carers complete pre on first session attended & post 3 months after*)
- Eight week programme of two hour Mindfulness and Therapeutic Exercise session (*carers complete pre before 1st sessions and post at last session*)
Implementation results to date