Appendix 1: Carer Breakdown

When a family carer can no longer continue to care

24/7 and 52 weeks of the year (no holidays!)

for the person they love

Caring for a loved one – husband, wife, partner, parent, friend – who has dementia is always very physically and emotionally tough – stressful, demanding, isolating, worrying, etc. When their loved one's symptoms and behaviour are relatively mild, they may be just frustrating and capable of it being assumed that "He/she is just getting old, forgetful, and a bit grumpy", but it is also the time when those closest, start worrying that there may be a deeper reason (dementia?). However, they very often feel embarrassed (even guilty) to go to their GP and ask for help. We hope that with national and local efforts to increase dementia awareness they will recognise that they need to "grasp the nettle" and seek to "find out". Of course, receiving a positive diagnosis is what they fear most, and being left in a world of uncertainty and worry for how they will cope with caring for their loved one as the illness progresses. However, there is a wealth of support in the Health, Social Care, and Community-based organisations that can help – "We can't take it away, but we can help to make it a lot better". This is what The Debenham Project has been all about for over more than 16 years.

- Symptoms of carer breakdown build gradually as one becomes more involved in managing day to day care. When one is constantly 'firefighting', it leaves little or no time for seeking support or self-care.
- Caring for a loved one 24/7 is exhausting both physically and emotionally and leaves little or no time for even basic self-care.
- Mental and physical wellbeing of the carer is key to preventing carer breakdown and the need for residential care.
- Managing care of a loved one and seeking the right kind of support is stressful. Finding time to speak to different agencies when seeking help is difficult when one is constantly caring.

Ultimately, carer breakdown directly leads to the need for a higher level of support from Social Care.

Nevertheless, the progression of the illness does inevitably reach the point when it becomes almost impossible for a family carer to survive the continual stress of caring for their loved one. However, the desire to love and care for their husband, wife, partner, parent, friend overrides their need to care for themselves and ends in Carer-Breakdown.

This almost always ends in a crisis requiring intervention by DIST, REACT & Social Care, or worse, hospitalisation, or even worse, a tragedy. Hopefully, it results in the introduction of professional assistance in support for the daily physical needs of the cared-for but rarely encompasses their social aspects, or the MH aspects of the carer's needs.

Carer Breakdown is the primary trigger for, following a crisis, an extended hospitalisation ultimately leading to permanent residential or nursing care for their loved one. The costs to the State and the family are huge.

The road to prevention of carer breakdown, or at least delaying the need for critical intervention, lies in interactively supporting the carer to be able to continue in their primary role of caring for

their loved one and handling all (24/7/52) that it involves. It means recognising that dementia is an illness of two patients, one with complex clinical neuro-MH-physical symptoms of a progressive illness, the other with complex clinical socio-MH-physical symptoms of a progressive caring induced mental illness. Meeting the needs of the cared-for must not dominate the needs of the carer.

“The carer can’t care if the carer isn’t cared for”