

Appendix 5a: Assessment for Inclusion in the Ongoing Initiative

It's quite difficult to define criteria for determining which families should be offered the opportunity to be provided with some respite support. Maybe our ultimate aim is to support any family within the project who seeks this type of support supplemented by our knowledge of the family? We would not wish to refuse anyone. We are all about inclusion.

1. Through observation and conversations with our families, we gained understanding of their needs and who were open to additional support.
2. The initial questionnaire informed us of the type of respite that would be beneficial and how it would impact.
3. Our aim is to offer respite to families before we observe carer breakdown in order to avoid or delay the need for crisis intervention, possibly leading to residential or nursing care.

Monitoring of carer experiences and improvement of well-being – key progress indicators. Carer feedback

We encourage our carers to give us feedback on the care they are receiving and how it can be improved. We are in close contact with the care company as they build positive relationships with the families.

Feedback from carers:

1. I can now attend a Pilates class which is supporting my physical and emotional wellbeing.
2. The carer gauges my husband's mood and is able to encourage him to go for a coffee.
3. This time gives me time to do a food shop in peace.

Co-production – asking, listening to and including carers.

Before and during the trial, past and current carer views were sought in both a verbal and written form. The feedback and comments are helping to refine and shape the ongoing delivery and future beyond the trial.

Carer breakdown, causes and implications

Causes

- Care breakdown builds 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.

Carer breakdown potentially leads to the need for a higher level of support from Social Care,

