Examples of patient (top) and carer (below) Pictor charts:

Interview extracts:

"Some days I just feel as though I want to get in the car and go, drive till the petrol runs out, doesn't matter where I drive to, as long as I'm away from it all, let some one else deal with it, you know"

“When it was all first started, I felt I was being pulled from pillar to post by everybody, I didn’t feel anybody was in charge of my treatment. Because I had him doing one thing, the doctor doing something else, I had the district nurse doing – I had lots of care, but too much...and I just wanted somebody if you like to co-ordinate the whole thing. And I think [this service] sort of more or less filled that”

“My wife trusts her too and I think that’s important because if anything did decide to go wrong I would like to feel like she had got somebody that she knew quite well and that she could talk to and if the worst came to the worst, you know, she’d be there afterwards as well”

Caring for a loved one at home was acknowledged as draining, but participants were effusive about the excellent at-home professional support they received from the specialist service. The care provided evidently recognised the needs of both patients and their families. Effective co-ordination of care, including liaison with other services was especially appreciated.

Pictor is a useful tool to obtain detailed insight into individual experiences of end of life care. Care co-ordination emerged as a key concern for patients and their families. It is vital that there are sufficient, well-resourced specialist palliative care services available in the community to support both patients and their families at the end of life.

The work described here was part of a larger evaluation undertaken for Macmillan by the authors and colleagues from the University of Sheffield. For further information, contact Joanna Brooks: j.m.brooks@hud.ac.uk

References: