

Background

- To deliver person-centred integrated palliative and end of life care, providers need to understand the experience and contribution of family carers in order to support the patient as best as possible.

Aim: To understand the relative contributions made by family carers, health and social care services and the Third Sector towards integrated care from a person-centred perspective.

Methods

- Using personal diaries, face-to-face contacts with providers during the **last 18 months of life** were extracted and coded for analysis.
- The carer and the long-term conditions coordinator of a patient with progressive supranuclear palsy (PSP) were interviewed in the year after the patient's death.

Diaries



Database

Year	Month	Day	Professional	Agency
2016	January	4	Long-term conditions coordinator	DHSC
2016	January	4	OT	DHSC
2016	January	5	Dietician	DHSC
2016	January	5	Physiotherapist	DHSC
2016	January	7	Physiotherapist	DHSC
2016	January	7	GP	DHSC
2016	January	9	Optician	DHSC
2016	January	12	Long-term conditions coordinator	DHSC
2016	January	12	Older persons community social worker	DHSC
2016	January	13	Hospice DU	3rd Sector
2016	January	15	Neuropsychologist	DHSC
2016	January	18	RDCH	DHSC
2016	January	19	RDCH	DHSC
2016	January	20	RDCH	DHSC
2016	January	21	RDCH	DHSC

January 2016 – June 2017

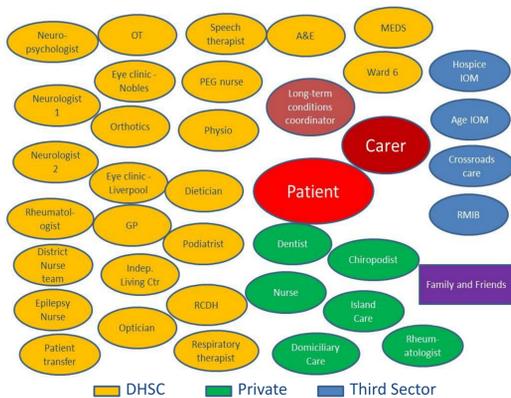
Analysis

- Each professional who provided care during this period was graphically represented by job role or agency (**Figure 1**).
- Number of contacts were plotted by provider of care (**Figure 2**) and purpose of care (**Figure 3**) for the 18 month period before death.
- Respite hours per month were subtracted from total hours in a month to estimate the number of hours the patient was cared for by her 78 year old carer/spouse (**Figure 4**).
- Quotations were extracted from interviews with carer and long-term conditions coordinator on integrating care.

Results

Patient's goal: "To stay home as long as possible until it's time to go to Hospice."

Figure 1. Ecosystem of care



"That was the main safety valve. She [Coordinator] appeared on the scene like a breath of fresh air. She made all the problems appear solvable." Carer

"A lot of carers feel guilt that they don't have the physical strength to care... I felt that I was failing if I needed help." Carer

"Trying to get them to accept respite took time. They would say 'Do we need it? Why do we need it?'... Sometimes the carer can see it as 'I'm not doing the job very well.'" Coordinator

Figure 3. Purpose of care provided in last 18 months

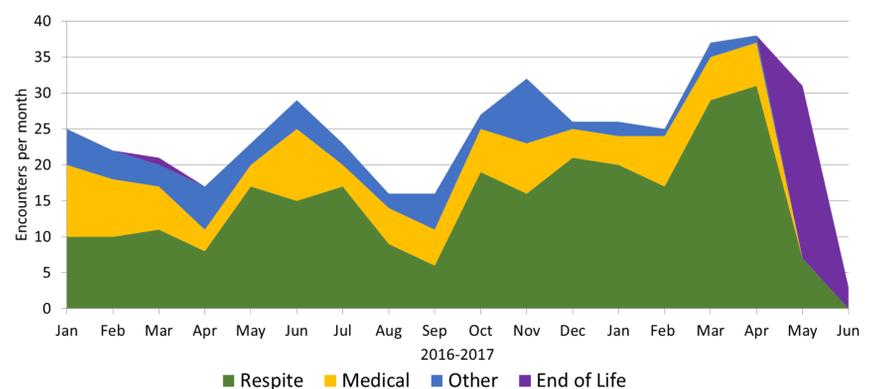


Figure 2. Encounters per month by sector

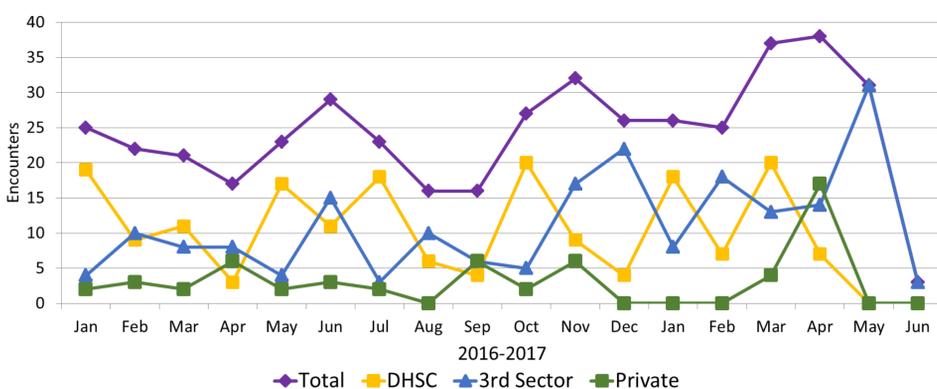
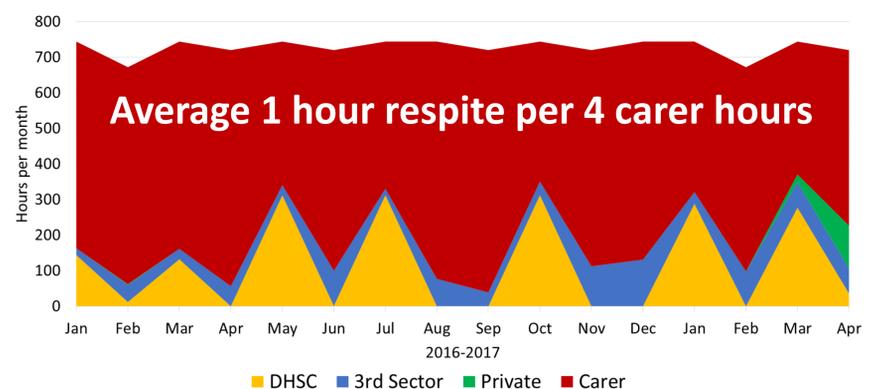


Figure 4. Hours of care provided by the carer and services by month



Conclusions

- Providing support to the carer with the navigation and coordination of services and respite enabled the patient to remain at home.
- The coordinator is key to identify the need for help and to offer help while remaining sensitive to the carer's perceived role in care.
- Despite the large number of professionals involved, the majority of services were intended to provide respite while the carer fulfilled the majority of day-to-day care of the patient.