

GSTT Caring with Carers Course: adapted for a community setting Project Evaluation

**Innovation Fund report prepared for NHS Lambeth CCG Management Team
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Introduction

In April 2017 Guy's and St Thomas' NHS Foundation Trust (GSTT) ran a free half-day training course for unpaid carers at the Whittington Centre, Streatham (a base for a range of the Trust's community health services). The course was an adaptation of an existing hospital-based initiative designed by the Trust to help carers of elderly family members with dementia prepare for their return home after a stay in hospital.

The aim was to test whether a course delivered in a community setting could help other family carers better support the person they care for and maintain their own wellbeing, with a view to reducing the need for unplanned GP and hospital appointments. The test was also intended as an attempt to better connect family carers with one of the new Local Care Networks (LCNs) and voluntary and community sector (VCS) services.

The initiative was tested with carers recruited from the SE Lambeth LCN catchment area and it was funded by NHS Lambeth Clinical Commissioning Group's (CCG) Innovation Fund. It was a partnership project by GSTT, Healthwatch Lambeth and SE Lambeth LCN Board. The idea was conceived partly in response to feedback from a family carer during Healthwatch's Going Home project which tracked transfer of care experiences after a hospital stay¹.

Healthwatch gathered feedback from participants attending the adapted course to find out how useful they found it, whether they had been able to apply any new learning and what difference this may have made.

Methodology

The course

The three-hour course included a self-care session and a choice of two 45-minute skills stations from the following four options: self-care and communication, personal care, moving and handling, and practical solutions for everyday life. Lunch was also provided. The course was facilitated by GSTT professionals including a district nurse and occupational therapist. The adapted features included:

- A community venue, the Whittington Centre, rather than a hospital-based session
- Promotion to carers of family members not currently in hospital
- Longer skills stations, extended from 30 to 45 minutes
- An offer of carer cover expenses in addition to travel costs
- An information pack on relevant VCS services (supplied by Healthwatch).

¹ Healthwatch Lambeth's Going Home project: www.healthwatchlambeth.org.uk/goinghome

Course promotion

The course was aimed at carers of adults with several long-term conditions and/or at risk of a fall, registered at a GP practice within the SE locality and using hospital services.

Course details were sent to: Carers Hub Lambeth, Carers4Carers, Age UK Lambeth's carer support worker, Project Smith Community Connectors, Healthwatch Lambeth's mailing list, GP practices in the catchment area and associated Patient Participation Groups (PPGs) via Lambeth PPG Network.

Attendees

Ten people attended the course. Of the nine who provided profile information, all were the principal carer for their loved ones. One participant was relatively new to the role, having started eight months previously but others had been carers for between three and 27 years. All but one cared for an immediate family member, with the exception supporting a neighbour/friend. One attendee cared for two family members. Half the attendees were caring for older people and half supported adult children with considerable or profound learning disabilities. Hours spent caring ranged from 12 to 35+ hours a week, with most describing it as a full-time occupation. Six participants said they received no hands-on support from other family or friends (although two families had paid PAs during the day), while another two attendees said family provided limited help. Half the attendees had received a carer's assessment and another person was expecting one. Six participants said they received regular support from their local Carers Hub (including one person who volunteered there), three carers mentioned help from Mencap and two attended sessions run by Carers4Carers.

Evaluation methodology

As part of the course participation agreement, attendees were asked to take part in two follow up interviews with Healthwatch to give feedback and share their experiences since the session. The aim was to interview participants within a week of the course and again six weeks later, to identify any outcomes and whether these had been sustained. Nine attendees agreed to be interviewed and eight initial interviews were carried out (two family members who both attended the course gave feedback together). Four follow up interviews were also completed (however one took place 13 weeks after the course due to holiday and other commitments). The lower number of second interviews was due to lack of interviewee time or non-response. All but one of the first interviews were face-to-face and all but one of the second interviews were by telephone.

Findings

Course experience feedback

Participant feedback on the course was largely very positive, with attendees describing the session as relaxed, friendly and professional: *'There were a good number of facilitators - it was a serious course, not lip service'* and *'[The facilitators] were down to earth and answered in full - I felt free to ask questions'*. One participant scored the session *'10 out of 10'*.

Highlights for participants included the opportunity to meet other carers and share insights: *'It was a sense of relief to hear other people's experiences.'* Participants also described it as respite: *'It gave me time to get away from my busy life and caring duties - it gave me "me time"'*. They also appreciated the opportunity to develop new skills for

self-care such as meditation and stretching exercises: *'Good techniques, useful common-sense stuff - probably stuff you could find online if you looked, but it saves time if someone is telling you about it.'*

Participants welcomed the chance to get positive feedback on what they were already doing well but also to learn new techniques or to update their skills: *'I used to be a nurse but things have changed so much since the 90s.'* Some also reported that the small group sizes allowed space for discussion. And although one person felt the course was more suited to less experienced carers, all interviewees felt they had benefited from attending the training.

However, several participants felt that there wasn't enough time to explore the individual *'nitty gritty of morning-til-night routine'* needs of each cared for person: *'There was a bit of commonality - but not enough. I didn't go too deep [into my loved one's issues]... it didn't feel fair to monopolise the time.'*

Similarly, while one person was surprised by the practical nature of the course, another felt the time was insufficient to practice the handling techniques being demonstrated.

Some attendees felt that the course was more suited to carers of older people, noting that the facilitators seemed unfamiliar with some conditions such as learning disabilities and people with very limited mobility: *'A lot of the things discussed were not useful in our situation or for our individual needs.'*

And while one participant reported that there was a lot of information to take away, another felt that the advice on accessing material support was less useful because *'the NHS keeps moving the goalposts.'* A couple of attendees also reported confusion around some topics: *'There was a bit about soap - I couldn't get a handle on the message'* and *'I want my wife to have the chance to have a good soak in the bath... It sounded strange to the facilitators.'*

Attendees also identified a range of topics which they felt were missing from the course such as how to recognise symptom progression, first aid, injection technique, handling challenging behaviour and skin care (which was due to be offered in the afternoon course that was cancelled due to low numbers - see page six).

There were also a few reported problems with the venue such as lack of space and noise from other sessions. One person also found it difficult to locate.

New learning

All participants reported new learning from the course and were able to give specific examples, ranging from practical tasks such as manual handling techniques and how to prevent pressure sores, to the benefits of using cream, using gloves for intimate tasks, and keeping someone covered up to prevent them becoming cold.

Softer skills were also identified such as moderating tone and volume when speaking and using non-verbal communication with a cared for person through touch.

Several participants highlighted the insights they gained for their own wellbeing as carers: *'The self-care module helped me to realise and appreciate how important it is for me to*

look after myself - the exercise on preparing for the day ahead was very helpful as I hadn't thought in that way before.'

Others felt that hearing the extent of other carers' responsibilities helped them to put their own situation into perspective. One participant, the former nurse, *'also learnt that it's OK to say "I don't know" and to ask someone... I used to feel helpless in the event of problems so it helped me a lot to feel able to ask.'*

A week on, all nine interviewees were reporting that they had applied this new learning and some had even passed on particular approaches such as mindfulness and handling techniques to other carer friends and family members. One individual also presented highlights from the course at their local Patient Participation Group meeting.

Several described experiencing tangible benefits from the daily relaxation exercises: *'I go out into the garden in the sunshine to do stretches - it feels good'* and *'My mood is always ready for the day after my morning exercise'*. Others relayed how the self-care content had prompted them to start taking better care of themselves in other ways: *'I'm looking more at my diet as I have diabetes - I've started buying more green vegetables'* and *'If a friend calls wanting something when it's my day off I now feel I can say no. I need to take time out for me.'*

The practical carer skills were also being applied successfully: *'I'm now much more careful when helping my husband move over to his side of the bed and I hold and support him differently when walking with him'* and *'I'm using feeling and touch more to communicate.'*

These approaches were still being practised by the participants we interviewed six weeks later: *'You put the fear of god into me thinking I'd break my father's collar bone! Now I'm being more patient and know I shouldn't precipitate movement'* and *'I'm still doing the breathing exercises about twice a week - they're useful'* and *'I bought some cream from the market - I think the skin is more moist.'*

Other benefits

All but one of the nine interviewees reported feeling more confident after the course: *'Yes - after the facilitators said "you're doing OK, carry on"'* and *'I feel more comfortable and more secure for me and for him'* and *'I have a positive outlook'*.

This confidence had sustained for those we spoke to a second time, particularly in terms of consciously thinking about how to carry out caring tasks, asking for support for the cared for person and speaking up about the carers' own needs.

Two interviewees in particular described how the course had resulted in or contributed to a significant, positive change in their family relationships. One participant felt they were less impatient and irritable with the cared for person and felt more able to accept the situation since the course: *'Seeing other carers in a worse position than me and discussing it with my [loved one] has helped me see things in perspective'*. For the other participant, the main impact of the course was *'getting validation that it's OK to walk away when you're stressed. It's normal'*. The carer explained how this significantly helped to change the dynamic within the wider family as the carer now felt able to put their personal unhappiness into the open and talk about how tiring caring can be. Family holidays were proving much more enjoyable since this change.

One participant relayed having a much more productive discussion during an appointment with an incontinence specialist following the course, resulting in the cared for person receiving the right continence pads: *'The course has given me more confidence to push for things... It makes me realise that there are things out there that I should get hold of.'* The carer felt this was particularly important in the knowledge that their loved one's health would deteriorate.

Other plans participants now had - prompted by the course - included: taking more exercise, looking up information on the topics of sessions they didn't attend, and getting on with tasks that had slipped down their priority list such as fitting grab rails. Two attendees were also motivated to find other opportunities for carer peer support. One explained: *'As I have been in Lambeth so long, I want to share my experience with other young carers in the community - to empower them and enable them to take control.'* The other planned to look for a carers group to join and was also lobbying for the re-establishment of a GP practice-based carers group.

Achievements against planned outcomes

This course had clearly succeeded in enabling the carers who attended to better support their loved ones in practical and emotional ways in their daily life. However, the majority of participants would have welcomed the opportunity for more tailored advice and support to reflect the particular conditions and needs of their loved ones.

The self-care aspects of the programme seemed to have had particular impact, equipping attendees with techniques which they were able to use and sustain, to not only maintain but improve their own wellbeing. For some, this had a wider impact on helping to support a more positive family dynamic.

However, six weeks on from the course - perhaps understandably - the participants reported no change in the need for unplanned GP and hospital appointments, apart from the positive exchange with the incontinence service described above.

Similarly, there was no evidence that attendees felt better connected to local health and care providers as a result of the course. Several participants felt confident to do their own research to find the information they might need, or felt they already had links with the right agencies to signpost them. However, some, including those with existing connections, were keen for more courses of this type: *'They shouldn't leave us alone.'*

When discussing the feedback from the course in July 2017, the SE LCN Board recognised the value of this type of programme and the benefits of embedding it within a wider support offer for carers. In particular, it was acknowledged that the care coordination multi-disciplinary teams currently in development and the new named professionals should be well placed to offer the tailored follow-up advice that the course participants were looking for. The LCN cohort criteria would also support more targeted promotion to maximise take up (see recruitment difficulties below).

The community venue, the other adapted element of the original course tested in this project, did not seem to offer any particular benefits compared to GSTT's hospital-based training facility, and none of the participants claimed travel or carer cover time expenses.

Other project learning

Recruitment difficulties

The course had capacity for 16 participants and was originally due to be run twice, offering a total of 36 places. However, only 10 people were recruited and the repeat session was cancelled. Promotion was delayed due to some confusion between the project partners regarding the development and coordination of a communications plan. There was also a misunderstanding between partners about the involvement of a PPG in the project. PPG members had expected to help shape the course content and publicity but this had not been envisaged by all the partners, adding to the complexity of the promotion task.

The publicity was released two weeks before the course but there was also difficulty in reaching the Independent Living and Carers Partnership (ILCP), a key promotion agency, due to staff shortages and sickness. A second round of promotional activity in the week before the course included a direct approach to six carers within the LCN cohort, identified by a relevant GP practice. One of these individuals attended the course but others expressed no interest, weren't available or felt they couldn't leave their loved one.

Similar initiatives

One of the ILCP partners, Help for Carers, had developed a similar course for family carers of self-funding customers of its own domiciliary care service. This was also a three-hour course covering moving and handling, 5 Ways to Wellbeing and mindfulness, first aid in the home and understanding dementia. The course was delivered in Mitcham the same week as the GSTT course by a range of agencies and professionals. The course was free to attend and well received, although participants also fed back that they would have welcomed longer sessions. Help for Carers is considering running the course quarterly for its self-funded customers and is keen to find ways to extend the offer to all carers.

The Carers Hub Lambeth is also working with Lambeth GP Federations and London South Bank University to develop a learning and support programme for isolated carers in the borough. Learning and connections between the two projects will be beneficial.

Next steps

GSTT secured funding from the Trust's Samaritan Fund for further caring with carers courses delivered at Guy's Hospital, with the final two still to be delivered, on 11 January and 28 March 2018. GSTT has widened the eligibility for these courses to any carers of Lambeth and Southwark residents meeting the same criteria of this test project. The Trust is also establishing a new Carers Hub for the thousands of un-networked carers using its hospital services.

Healthwatch will share the learning and our evaluation approach used for this initiative with the other Lambeth carers training project to help maximise insights from the test.