



# Time To Think About You

Supporting carers to look  
after their own health

November 2016

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## Introduction

The Health Innovation Network is the Academic Health Science Network for South London, one of 15 AHSNs across England formed to pioneer new and innovative ways of creating system-wide improvements in patient and population health.

We are a membership organisation, focused on driving lasting improvements in health and wellbeing for our diverse local communities across South London. We are working with industry partners driving innovation to improve health across our clinical areas - alcohol, dementia, diabetes and musculoskeletal.

Our cross-cutting themes - patient safety, patient experience, information and technology, wealth creation, and capacity building run through all our work programmes.

There has been significant emphasis on increasing diagnosis rates of people with dementia in recent years. Whilst this is to be encouraged, it is also important to ensure that good quality post-diagnostic support is available to people and their carer(s) once they have been diagnosed. The Alzheimer's Society estimates that there are over 670,000 people in the UK acting as primary, unpaid carers for people with dementia, saving an estimated £11 billion each year (Alzheimer's Society, 2014). Carers are twice as likely to suffer from ill health as non-carers.

**The aim of this project was to encourage family carers of people with dementia to look after their own health and access the support they need from their local GP surgeries and carers' centres.**

The project was led by a Darzi Fellow (a GP in Southwark), working in the dementia team at the Health Innovation Network during 2015-16 who recognised the problems faced by GPs when trying to support carers effectively.

*"In my experience as a GP based in Southwark, London, carers present in many different ways but most often in a crisis. A history needs to be unpicked until you may even realise they are a carer. They have problems that are common to us in primary care such as depression, pain, difficulty sleeping and a general feeling of being overwhelmed or quite simply fatigue. They are often the ones who may have missed their annual checks and are not compliant with their medication. No GP can ever promise to solve every problem in 10mins, although it is a challenge we are often confronted with, but often the start to helping a patient through their concerns is saying that their feelings are valid and starting a journey to helping them through either by managing within the surgery setting or referring to the appropriate service. Moreover, carers may be the ones who do not think to see us at all and for this reason carers' health may well start outside of the surgery doors." - Dr Nwakuru Nwaogwugwu, Darzi Fellow*

We would like to thank the following carers groups, centres and leads for their invaluable contributions:

- Wandsworth Carers Centre
- Bromley Carers Centre
- Richmond Carers Centre
- If only I'd known Known carers support group: Southwark

In addition we are grateful for the support and feedback of colleagues and general practitioners whose input further shaped the final design of Time to think about you.

## Project Team

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## Executive Summary

There is substantial evidence that unpaid carers often neglect their own health and as a result experience health inequalities. More than half of those who provide more substantial care have suffered physical ill health as a result of caring and more than 70 per cent of those caring round the clock have suffered mental ill health at some time (NHS England, 2016).

The Health Innovation Network Dementia Programme team worked with informal, unpaid carers, health and social care professionals and the Carers Trust, a major national carers' charity, to develop an approach to encourage carers of people with dementia to look after their own health and access the support they need from their local GP surgeries and carers' centres.

We worked with local carers to co-design a tool called 'Time to think about you' to support carers or people with dementia to think about their own health and prompt them to seek help from general practice and carers centres. Carers of people with dementia were consulted about how they think about and prepare for GP appointments. Their input informed the design and content of 'Time to think about you'.

'Time to think about you' includes a definition of a carer, and a list of 'prompt' questions to carers about common problems which might indicate a health problem. If the answer to any of these questions is 'yes', carers are encouraged to make an appointment with their GP.

The tool also includes the contact details of the local carers' centre and a tear off slip to be handed to GPs to request them to record on their system that the patient is also a carer.

'Time to think about you' was then tested in three local carers' centres over a six week period. Each centre disseminated the prompt card to known carers along with stamped addressed feedback forms. Feedback was also sought from carers centre staff and local GPs by telephone and in person.

11 feedback forms were returned. Although only one of the carers had had the opportunity to use 'Time to think about you' with a health professional, all the carers said it was useful.

***'I wish I had known about this [Time to think about you] 3 years ago'  
(A carer of someone with dementia)***

Health and social care professionals also fed back positively and suggested that 'Time to think about you' has relevance to most carer groups, not just carers of people with dementia.

***'It is an excellent idea. .... many GPs are not only swamped with waiting rooms bulging with patients, but that a good deal will not be accustomed to supporting a carer with their stresses in any other way than to prescribe a pill like an anxiolytic or antidepressant - which is not necessarily the answer.'  
(Dementia Practice development consultant)***

In response to feedback about the tool from GPs, we adapted 'Time to think about you' to include 'Read codes' to make it easier for GPs to identify patients as carers on their IT systems.

'Time to think about you' is available in a variety of formats and can be downloaded from the Carers' Trust website: <https://carers.org/timetothinkaboutyou>

# Background

## Impact of caring on carers

The Carers Trust report, 'A road less rocky' (Newbronner, Chamberlain, Borthwick, & Baxter, 2013), suggests that there are key points on the carers journey where information and support is most needed [see box 1].

The NHS England toolkit 'An integrated approach to identifying and assessing carer health and wellbeing' (2016) states that 'the carers' primary care team has a crucial role in initiating the discussion about the carers' support needs and in supporting and maintaining carer health and wellbeing. The primary care team also has a crucial role in identifying carers.

However, research has shown that carers do not address their own mental and physical health needs for several reasons:

- Concerns about wasting the doctor's time (L. H. Burrige, Mitchell, Jiwa, & Girgis, 2011)
- Issues with physically accessing the GP (L. H. Burrige et al., 2011), especially where the person being cared for has mobility problems, has challenging behaviours or has entered a situation of end-of-life care.
- In a GP consultation carers may wait for 'validation or permission' to explore issues that concern them (L. H. Burrige et al., 2011).
- They may be overwhelmed by a plethora of problems, with their own health concerns effectively being subsumed by other matters. (L. H. Burrige et al., 2011)

GPs' capacity is limited and they may be overwhelmed if a carer presents with a wide range of health and social concerns (L. H. Burrige et al., 2011).

A Royal College of General Practitioners report (2103) describes how ten motivated practices from around England have improved the identification and support of carers. All the exemplar practices have developed a close relationship with their local carer support organisations and highlighted this as a key aspect of their carer support services. General practices can find it challenging to keep up to date with what services and benefits are available locally and nationally for carers. The exemplar practices shared that they have found it makes sense to direct carers to their local carer support services, who have detailed and current knowledge about what is available, and can advise them or refer them on to other providers.

### Box 1. Key points in the dementia journey

1. When dementia is diagnosed.
2. When the carer takes on an 'active' caring role.
3. When the capacity of the person with dementia declines.
4. When the carer needs emotional support and/or a break from caring.
5. When the person with dementia loses their mobility.
6. When the person with dementia has other health problems.
7. When the carer has to cope with behaviour problems.
8. When the carer's own circumstances change.
9. When the person with dementia becomes incontinent.
10. When decisions about residential care and end of life care have to be made.

The Carers Trust propose that appropriate intervention, information and support at these 'key' times in the caring role were likely to result in improved caring experiences.

(Newbronner et al., 2013)

The Chief Executive of the London branch of the Carers Trust highlighted the importance of building and maintaining a reciprocal triangle between the carer, their local Carers Centre/support service, and their GP. An effective triangle would facilitate communication, be supportive and aim to support carers holistically.

The project objective was to develop a tool to:

- prompt carers to look after their own health and seek support from primary care and carers centres.
- support GPs to recognise carers and support them in their caring role.

## Our Approach

### Listening to carers

To understand what would be useful in supporting dementia carers to think about their own health, we ran focus groups with:

- Southwark 'If only I'd known' dementia carers support group
- Wandsworth carers centre dementia support group

Each group was made up of seven to ten dementia carers at different stages of the caring journey. The discussions focussed on key areas:

- 1. Planning and preparation prior to seeing a GP**
  - Including how preparation might take place and if it made a difference to the GP consultation
- 2. Prompts and events that lead to making a GP appointment**
  - Triggers for making appointments and who they choose to see e.g. GP or nurse
  - If appointments for the carer and the person being cared for are helpful if at the same time.
  - Topics that they would not raise with a GP
  - Types of appointments: telephone, home visit, email, double appointments
- 3. Their feelings while in an appointment**
  - Factors that prevent carers mentioning specific issues about themselves or the person they care for
  - If carers felt their GP can cope with whatever they may be going through

Feedback from the focus groups indicated that they would find a 'prompt card' useful and were keen to support its design. The key messages from the focus groups on design and content were:

- **Avoid questionnaires and tick boxes** – the focus groups felt they had often had enough forms to fill in and a questionnaire felt like more work and just another tick box exercise. They wanted something that was brief and could help act as a prompt.
- **Keep it brief**
- **Focus on carers** - The carers already felt overwhelmed with information about 'how to care'. They liked the idea of focussing on themselves.
- **'Time to think about you'** – was an acceptable title for the tool, they felt it helped focus events on themselves.

## Design

The first draft of 'Time to think about you' included a set of health and wellbeing questions which served as the prompts, a definition of a carer and space to insert local carer information contact details and a tear off slip to inform the GP that their patient is a carer (figure 1).

## Testing

The draft prompt card (figure 1) was then tested in three local carer's centres:

- **Wandsworth carers centre**
- **Richmond carers centre**
- **Bromley carers centre**
- Each centre disseminated the prompt card to known carers along with stamped addressed feedback forms. The questions and responses are listed in table 1.

Feedback was also sought from carers centre staff and local GPs by telephone and in person.

## Results

11 feedback forms were returned, and although only one of the carers had had the opportunity to use 'Time to think about you' with a health professional, all the carers said it was useful. Seven carers rated the usefulness of 'Time to think about you' as Very Useful, and three carers rated it as Quite Useful. No carers rated it as Not Very Useful or Not At All Useful.

When asked to explain how they found it helpful, carers commented:

- As a carer this seems to be an excellent idea
- Formalises role with GP
- Because it summarises the feelings and situations of carers
- The leaflet helps to quantify concerns and problems when it is hard to put things into words
- I didn't think I would talk to the GP about my problems
- Do not find the time
- Sometimes I would like to talk to someone
- Time to think about you information is very useful to know
- Keeps caring on the agenda

The tool was also shared with partner organisations and colleagues who had an interest in dementia care and their feedback collated.

The figure shows a prompt card with the following content:

- Logos:** carerstrust (with tagline 'ACTION INSPIRE SUPPORT') and hin (Health Innovation Network South London).
- Title:** Time to think about you. Information for carers, families and friends. (Accompanied by a blue mug icon).
- Section: Are you a carer?**
  - Definition: A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support.
  - Questions:
    - Do you feel you do not have enough time for yourself?
    - Has caring stopped you from doing what you enjoy?
    - Has caring made it difficult for you to work or do whatever else you have to do?
    - Is your own health affected as a result?
    - Do you feel unable to cope?
    - Do you feel you are under too much pressure?
    - Do you have no one to talk to about your concerns?
    - Do you feel low?
    - Are you sleeping poorly?
    - Are you not eating properly?
    - Are you tearful, angry and/or anxious?
    - Do you have concerns about your own memory?
- Section: IF YOUR ANSWER IS YES TO ANY OF THESE, THIS IS WHAT YOU CAN DO:**
  - Go and see your GP.
  - Take this card with you to explain your worries.
  - Place centre information here (in a box).
- Section: Please complete and hand this slip in to your GP surgery**
  - Dear GP,
  - I am a carer. Please make a record of this in my notes.
  - The person I am caring for is/is not registered at the surgery.
  - I have/have not registered at the local carers centre.
  - Print name: \_\_\_\_\_
  - Date of birth: \_\_\_\_/\_\_\_\_/\_\_\_\_



# Feedback & Discussion

## Study limitations

- We received 11 formal feedback forms from the three centres and one person had had the opportunity to use 'Time to think about you' with a health professional. Although a small sample the overall response to 'Time to think about you' was positive.
- Younger carers would benefit from a different version of the card themes more relevant to their age group. For example, the logo could reflect a younger theme and some questions could be framed differently, e.g. how caring impacts on school attendance, sitting and preparing for exams, interfering with work commitments and so on.

## Feedback about the design and content

The design and layout of the card has been welcomed across all professional and carer groups.

*'Staff response is that they like the general look and feel of the card'*  
**(Carers centre lead)**

## Feedback about the questions

We found that carers used the card intuitively without needing further instructions. Additional questions, such as finance and respite care, were commonly suggested to be included in the prompts. But we wanted to respect the key themes from the focus groups, keep the card as simple as possible and consider areas that GPs could either address directly or through existing referral systems. Social aspects of caring are often addressed during formal carers assessments and referrals from GPs to carers centres and vice versa would maintain the triangle of support.

*'My first impression is that the questions are sound. However, some information as to what can be provided, what filling the form in or contacting carers centre etc. will lead to would be of benefit. I think there has to be some 'What is in it for me?'*  
**(GP Lewisham)**

## Feedback from GPs

Some GPs suggested that the card could be more explicit in supporting GPs to record the person as a carer on their IT system by including the relevant 'Read code'. Read codes provide the standard vocabulary by which clinicians can record patient findings and procedures in health and social care IT systems. In response to this feedback, we adapted the tool to include the specific Read codes for identifying carers.

There were some concerns that GPs might not be able to manage carer problems or may not have time to deal with carer issues either due to a poor understanding or a lack of time.

### **Question to a GP:**

*Would you worry about increased GP demand for appointments?*

### **Answer:**

*No, they need them. They don't look after themselves and have real health issues, my highest ever recorded hba1c of 140 was in a carer undiagnosed because she didn't have time to see the GP'*  
**(GP Bethnal Green, East London)**

There was an overwhelming feeling that carers needed support and that GPs were keen to provide it where they could.

*‘Just thinking about what is the benefit of this form for the patient and the GP....for the patient, it would be useful for them to trigger a discussion about some of their issues and help them realise it is something they can talk to GP about and perhaps get help with. For the GP, it would help if someone had thought about their issues before hand and could then focus on solutions a little better.’*  
(GP Lambeth)

## Conclusions

‘Time to think about you’ has been warmly welcomed by a range of stakeholders including carers, carers’ organisations, GPs and local authorities. Guys and St Thomas’s hospital’s dementia team have included ‘Time to think about you’ in their dementia carers pack and Southwark and Lambeth Alzheimer’s Society Dementia navigators are using it with carers in the community. The three carers centres which tested ‘Time to think about you’ are continuing to use it.

Although ‘Time to think about you’ was initially developed for carers of people with dementia, we have found that the questions are relevant to carers of people with other long term conditions, so this has increased its potential relevance. The ability to provide localised contact details of carer’s support services has been particularly welcomed by organisations in other parts of the country.

‘Time to think about you is’ is important as it reinforces the message to GPs to maintain good links with the local carers’ centre, as this is where carers can access a range of practical and social support. It also helps GPs maintain a carer’s register which helps them plan treatments and target campaigns, such as flu vaccinations for carers, as well as looking out for warning signs of illnesses that are common among carers, such as back pain resulting from heaving lifting or stress.

By co-producing with the Carers Trust and carers and testing the tool in carers centres we have developed a tool that is relevant and valuable to carers, can complement existing carer support within most settings, assists GPs in providing better carer support and is available free for use nationally.

### The ‘Time to think about you’ bundle

We have produced different versions of the tool which can be used flexibly according to the setting. The bundle is available on the Carers Trust website and includes:

- Time To Think About You A4 fold over
- Time To Think About You A4
- Time To Think About You Poster (can be printed as A3 or A4)
- Time To Think About You Mini cards

All ‘Time to think about you’ resources are available on the Carers Trust website:  
<https://carers.org/timetothinkaboutyou> for professionals  
<https://professionals.carers.org/timetothinkaboutyou> for carers/general public.

## References

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# Time to think about you

Information for carers, families and friends



## Are you a carer?

A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support.

- Do you feel you do not have enough time for yourself?
- Has caring stopped you from doing what you enjoy?
- Has caring made it difficult for you to work or do whatever else you have to do?
- Is your own health affected as a result?
- Do you feel unable to cope?
- Do you feel you are under too much pressure?
- Do you have no one to talk to about your concerns?
- Do you feel low?
- Are you sleeping poorly?
- Are you not eating properly?
- Are you tearful, angry and/or anxious?
- Do you have concerns about your own memory?

If your answer is YES to any of these, you can visit your GP or local carers' centre and take this card along with you.

For more information or to download this resource visit [www.carers.org/timetothinkaboutyou](http://www.carers.org/timetothinkaboutyou)

Add your centre address here



Please complete this slip and hand in to your GP during your next appointment

Dear GP,

Name of carer: \_\_\_\_\_

Date of birth: \_\_\_\_/\_\_\_\_/\_\_\_\_

*This patient is a carer. You may find it helpful to read code this information in their clinical records. It will help maintain your carers register. Please use the appropriate read code for your GP software:*

	Read 2	CTV 3
Is a carer	918G	UaOVL

Table adapted from RCGP Caring for carers [<http://caringforcarers.info/kensingtonandchelsea/resource/read-codes-for-carers/>]