An Analysis and Evaluation of the Admiral Nursing Direct Dementia Helpline

Sue Wilkinson
Department of Sociology, University of York
April 2016
Dementia affects the whole family so we support the whole family
Background

Dementia UK is a charity committed to helping families face dementia. Its network of Admiral Nurses provides specialist one-to-one support and expert advice to help families “cope with the fear, uncertainty and difficult everyday reality of dementia” (www.dementiauk.org/how-we-help/). The charity’s Admiral Nursing Direct dementia helpline is a key part of its work. The helpline is staffed (five days and two evenings a week) by trained Admiral Nurses, who also provide an email service. The helpline is advertised on the Dementia UK website - as being for “family or professional carers of someone with dementia, people dealing with a diagnosis of dementia, and those worried about their memory or the memory of a loved one” (www.dementiauk.org/how-we-help/admiral-nursing-direct/).

Overview Of The Study

This study is an analysis and evaluation of the Admiral Nursing Direct dementia helpline, based on a sample of recorded calls. It provides an overview of the service; and a more in-depth analysis some key features of the calls. It highlights what is done particularly well (and offers some pointers towards what could possibly be improved).

To facilitate co-production of research questions, the study was developed in consultation with a stakeholder steering group including key staff at Dementia UK and service user representation. It was approved by the Loughborough University Ethical Advisory Committee. Six call-takers on the Admiral Nursing Direct (AND) helpline recorded a sample of their calls during the period March-November 2014, with informed consent from callers. All calls were fully transcribed and anonymised prior to analysis. Key variables were then coded for analysis. The analysis used a mix of content and thematic analysis (Braun and Clarke, 2006) and conversation analysis (Sidnell and Stivers, 2013). An interim report was produced and discussed with the steering group in February 2015 – these discussions ensured that the final decisions about what to analyse were co-produced between researcher and stakeholders.

Method

Evolution of the study

The study was originally envisaged as encompassing an analysis of 30-50 hours of recorded calls from 3-4 call-takers. This was based on the assumption that typical call length is around 30 mins, and that each call taker would record 20-30 calls (i.e. providing a data set of around 100 calls for analysis). Due to the enthusiasm of the AND nurses staffing the helpline, the study more than doubled in scope, eventually encompassing over 300 calls from 6 call takers. Many calls are much longer than 30 mins (with some as long as 90 mins).

Recording and transcription

In accordance with the approved ethics protocol, call-takers undertook to obtain the informed consent of callers for recording (and were provided with a ‘script’ for seeking consent). Refusals to record (of which there were very few) were taken as final and the call was not recorded. Any calls which were recorded, but for which consent was not obtained, were not included in the sample. A total of 324 calls were recorded, with consent, between March and November 2014, from six call-takers. Twelve calls subsequently had to be discarded due to poor quality of the recordings. Seven further calls were immediate call-backs (e.g. because the call had been cut off, or to get a better line) – each of these seven was treated as a continuation of the prior call. This generated a final sample of 305 calls for analysis.

The number of calls provided by each call-taker was as follows:

- Call-taker A: 82 calls
- Call-taker B: 57 calls
- Call-taker C: 23 calls
- Call-taker D: 86 calls
- Call-taker E: 33 calls
- Call-taker F: 24 calls

The sample of 305 calls is opportunistic, rather than representative of all calls received during the nine-month recording period, as call-takers either did not record or limited their recording at times when they were particularly busy; also (with one exception), new recruits to the helpline during the recording period did not join the study.

The recorded calls were transcribed by a professional agency experienced in working with sensitive medical and legal data, and anonymised prior to coding.

Data coding

The initial coding frame was developed on a subset of 84 calls (i.e. around a quarter of the sample). It was subsequently revised in consultation with the stakeholders, following discussion of the interim report.

In the final coding frame, 15 variables were coded systematically, as follows, in order to provide a basis for analysis:

1. Status of call (i) – direct or call-back
2. Status of call (ii) – first or subsequent
3. Status of caller – PWD, carer or professional; sex
4. PWD living arrangements
5. Banner headline(s) for ‘problem presentation’
6. Complaint
7. Donation
8. Praise/thanks offered by caller
9. Key aspects of caller response – types of support
10. Advice-giving
11. Support/care-giving
12. Other points of interest
13. Info to be sent
14. Call back offered
15. Note of calls handled particularly well/less well
Most of these variables were sub-divided for additional coding – full details of the final coding frame are given in Appendix 1.

Coding of the data for analysis was undertaken by two expert coders, with substantial experience in analysing interactional data. They listened to the recording in conjunction with reading the transcript for each call (and making any necessary corrections). While listening, they systematically recorded information about each of the fifteen variables on an Excel spreadsheet. They also collated more detailed qualitative data on variables 5, 8-12 and 15 – together with explanatory and additional notes – in Word documents.

Data analysis
Analysis initially consisted of a statistical summary and content analysis of (most of) the coded variables, based on the spreadsheet data (Part (i)). Some variables were combined (as noted below), and one was omitted for lack of data (variable 7 – donation - only 3 values were recorded). The following framework was used:

- Demographic characteristics of calls (variables 1 and 2)
- Demographic characteristics of callers (variable 3)
- Demographic characteristics of PWDs (variable 4)
- What calls are about (variable 5)
- Complaints (variable 6)
- Praise/thanks (variable 8) – see also Appendix 2 for examples
- Supporting the caller (variable 9)
- Call follow-ups (variables 13 and 14)

Subsequent analysis consisted of in-depth thematic analyses of key aspects of call-handling, based on the qualitative data collated in Word documents for several of the variables (Parts (ii) and (iii)). Part (ii) reports this analysis for variables 9-11 (key aspects of caller response; advice-giving; and support/care-giving). Part (iii) reports this analysis for variables 12 and 15 (calls handled well/less well; and other points of interest). Conversation analytic techniques were also used in this subsequent analysis to examine certain aspects of call-handling – particularly how callers offer advice, understanding and empathy.

Results
The results of the study are presented below in three sections:

- Part (i) Overview of the helpline service
- Part (ii) Detailed analyses of call-handling
- Part (iii) Call-taker practice & other points of interest

Part (i) Overview of the helpline service
This section provides an overview of the AND dementia helpline service in mid-2014. It is based on a statistical summary and content analysis of the key variables listed above. This summary includes analyses of the demographic characteristics of the calls, the callers, and the people with dementia (PWDs) under discussion. It also includes analyses of the content of the calls: in terms of problems presented, complaints, praise & thanks, supporting the caller, and follow-ups offered.

Demographic characteristics of the calls
Calls were coded according to whether they were taken as they came in, or were call-backs in response to a message on the helpline answerphone. Nearly three-quarters of the calls (70%, N=214) were call-backs. Only 11% of calls (N=34) were taken as they came in (the coders were unable to tell in the remaining 19% of calls [N= 57]).

The number of call-backs can be considered as an index of the high volume of calls coming in to the helpline at any one time, insofar as a call-taker engaged in an (often-lengthy) call is not available to take other calls for the period of its duration. The necessity of making so many call-backs also has implications for the workload of the call-takers and – potentially - for the satisfaction of callers, who may have to wait some time for support and advice (although there were no complaints about this).

Calls were also coded according to whether they were first or subsequent calls to the helpline. The majority (56%, N=171) were first calls, but a significant minority (21%, N=63) were follow-up or subsequent calls (the coders were unable to tell in the remaining 23% of calls [N=71]). The proportion of subsequent calls is higher than on many other similar helplines, and is an index of the high degree of continuity of support provided by the AND helpline.

Demographic characteristics of the callers
Callers were categorised, wherever possible, into: family members and other carers; professionals; and persons with dementia (PWD) themselves. It was possible to categorise 269 (77%) of the 305 calls in this way. The vast majority (96%, N=259) of these 269 calls were from carers (or others closely involved with the PWD), and most of these were family members. The relationship of the carer to the PWD is shown in Table 1 below (percentages are rounded up to the nearest whole number):

<table>
<thead>
<tr>
<th>Carer of PWD</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daughter</td>
<td>134</td>
<td>52</td>
</tr>
<tr>
<td>Son</td>
<td>48</td>
<td>19</td>
</tr>
<tr>
<td>Wife</td>
<td>24</td>
<td>9</td>
</tr>
<tr>
<td>Husband</td>
<td>16</td>
<td>6</td>
</tr>
<tr>
<td>In-law</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Friend</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>Other</td>
<td>22</td>
<td>9</td>
</tr>
</tbody>
</table>

More than half of carers are the daughters of PWDs. ‘Others’ include: ex-wife, brother, sister, father, granddaughter, uncle, niece, cousin, great nephew, neighbour, neighbour’s daughter, and friend’s mother. The proportion of female carers overall closely reflects the national figure of 60-70% (Alzheimer’s Research UK, 2015).
Eleven (4%) of the categorised callers were healthcare professionals calling about a PWD (and in two cases a daughter had nursing qualifications). Only one caller was unequivocally a PWD, calling on his own behalf (although some of the relatives of PWDs expressed concern about possibly developing dementia themselves).

**Demographic characteristics of the PWDs**
Where applicable, the sex of the PWD under discussion in the call was coded. Due to a coding error, this was only done for two-thirds of the calls (N=203; 67%). In these, 63% (N=128) of the PWDs were female; and 35% (N=71) male. (In the remaining 2% (N=4) of calls, two PWDs were discussed – in each of these, both parents of the caller had dementia.) This reflects almost exactly the statistics on sex differences in dementia in the UK (61% women, 39% men), according to the most recent report from Alzheimer’s Research UK (2015).

Where possible, the living arrangements of the PWD were coded. These are shown in Table 2 (%s based on 269 calls).

| Table 2: Living arrangements of PWD |
|-------------------------------|---|
| N %                             |   |
| Own home (total) 140 52          |   |
| – with someone 97 36            |   |
| – alone 43 16                   |   |
| Caller’s home 49 18             |   |
| Institution 53 20               |   |

More than half of the PWDs for whom living arrangements were coded (N=140; 52%) live in their own home: two-thirds of these with someone (usually a spouse); a third alone. The remainder live either with the caller (usually an adult child), or in an institution (including sheltered accommodation and care homes).

Taken together, the demographic findings above suggest that the "typical" caller to the AND helpline is a daughter who cares for a mother with dementia in the mother’s own home.

**What the calls are about**
To give a sense of the range and diversity of the calls, up to three ‘banner headlines’ - i.e. the problem(s) presented by the caller - were generated by the coders to summarise the content of each call. A qualitative content analysis of these ‘banner headlines’ was undertaken to identify the most commonly reported problems across the data set.

These problems were:
- Medication problems
- Eating problems
- Safety issues
- Activities
- Communication
- Living arrangements, especially problems associated with move from own home to care home
- Respite care/carer exhaustion
- Decline in carer’s own health/living too far away to help
- Problems with care agencies/care facilities
- Finance/Power of Attorney
- How to manage sudden deterioration or specific crisis
- Request for info about AN services
- Request for general info about dementia/what to expect in future

Clearly, this list alone does not do justice to the richness and complexity of the calls, or to the extent and quality of engagement needed from the call-takers (see also parts (ii) and (iii) of the Results).

**Complaints**
More than a quarter of the calls (N=85; 28%) included some kind of complaint about health and social care services and support. (These were not analysed any further, as not directly relevant to the AND dementia helpline service.)

**Praise and thanks**
One index of the effectiveness of the helpline is the praise, appreciation and thanks spontaneously offered by callers. The vast majority of calls (N=277; 91%) included thanks from the caller, and often also praise for, and appreciation of, the helpline service. Three callers also offered a donation to Dementia UK. Callers typically offered more – sometimes much more – than a basic "thank you" for the call-taker’s help. For example, they said: “I’m so grateful”; “I really appreciate that”; “I think you’re brilliant”; “thanks ever so much”; “Thank you for all your valued support”; “Thanks very much indeed for all your help”; “Thank you so much for that”. Sometimes the praise and thanks offered was even more extensive and/or effusive. A more extensive selection of praise and thanks (across all call-takers) is included as Appendix 2.

**Supporting the caller**
In around a third of the calls (N=93; 31%), the callers talked about the effects of caring they themselves were experiencing. These typically included frustration, distress, exhaustion and not knowing how to cope and/or where to go for help. In response, call-takers offered practical, emotional and informational support to callers. Practical support was offered in around two-thirds of the calls (N=192; 63%); emotional support in more than half of the calls (N=163; 53%); and informational support in 80% of the calls (N=243). Many calls involved more than one type of support. The provision of practical support and emotional support is examined in more detail in Part (ii) of the Results.
Call follow-ups
The call-takers were very good at offering follow-ups to the calls. In about a third of cases (N=119; 39%), they promised to send the caller follow-up information, either by email or by post. In about two-thirds of cases (N=192; 63%), they invited the caller to ring back for further help and/or if they had any additional concerns. This probably accounts – at least in part - for the relatively high proportion of subsequent calls in the sample, as noted in 4.1 above. In a few cases, call-takers undertook to make a follow-up call to the caller at a specified point in time. Of course, follow-ups will not be appropriate for every call (particularly those from professional callers).

Part (ii) Detailed analyses of call-handling
Aspects of call-handling were coded very extensively - and not all of this material has been fully analysed. This section will focus on three aspects of call-handling that are central to the AND dementia helpline service, and of particular interest to the stakeholders:

- (a) Giving advice
- (b) Balancing the needs of the PWD and the caller
- (c) Providing emotional support: understanding and empathy.

(a) Giving advice
In more than three-quarters of calls (N=237; 78%), specific advice was provided to the caller. The most frequent areas/types of advice concerned: professionals, the care system, living arrangements, medication and self-care. Other areas/types of advice included: diagnosis of dementia, services, safety, eating, activities, communication, and finance. These areas of advice map broadly onto the ‘banner headlines’ for problems given in 4.4 above. In more than half of the calls overall – and more than three-quarters of the calls which offered specific advice (N=163; 69%) - this advice was accompanied by emotional support for the caller (see 5.5 below).

Conversation analysts (e.g. Emmison and Firth, 2012) have documented some of the ways in which advice-giving practices on telephone helplines can reflect their institutional remit and guiding policies. Admiral Nurses work aim to help families to cope with the “difficult everyday reality of dementia”. This undertaking is apparent in several of the ways in which advice is delivered on the helpline. Here are two examples:

Suggesting daily management strategies
Most of the calls (N=243; 80%) included discussion of the difficulties the caller was experiencing on a day-by-day basis with the PWD for whom they were caring (see ‘banner headlines’ in Part (i) above for typical problems). In response to these day-by-day difficulties, one distinctive practice frequently employed by call-takers was to suggest specific practical and/or psychological strategies to help the caller manage the situation.

Practical strategies were things like:
- “Have part of the meeting at the house”;
- “Stick it up on the fridge on a magnet”; or
- “Get your mother to agree to your going to the GP with her”.

Psychological strategies were things like:
- “Give him something to make him feel good about himself”;
- “Talk about how special it was to him … it’s not just a pair of socks he’s lost”; or
- “You can perhaps try what they call validating his feelings – then at least he knows you know how he feels”.

Practical strategies were suggested in around two-thirds of the calls overall - and in more than three-quarters of the calls in which day-by-day difficulties relating to the PWD were discussed (N=188; 77%). Psychological strategies were suggested in around a third of the calls overall – and in well over a third of the calls in which day-by-day difficulties relating to the PWD were discussed (N=97; 40%). This practice is both a form of advice-giving and a means of supporting the caller - in a very practical way. It is also reflective of the considerable expertise of the call-takers in the management of dementia.

Offering ‘script proposals’
Offering a ‘script proposal’ (Emmison, Butler and Danby, 2011) involves giving a caller an example of what they might say in a given situation (in effect, a ‘script’ they might follow). The script is presented in the first person – i.e. the call-taker ‘voices’ the words of the caller in order to ‘model’ what he or she might possibly say.

As with the practice of suggesting daily management strategies, offering a script proposal is both a form of advice-giving and a means of supporting the caller in a very practical way. It is particularly skilled technique because it requires the not only extensive background expertise in the kinds of issues under discussion, but also the ability to assess, there and then, what kind of a script is likely to ‘work’ for that particular caller, on the basis of what he or she has already said. Tailoring a script to a caller, based on his/her individual situation and particular needs, is known in the conversation analytic literature as ‘recipient design’ (Wilkinson, 2011). Maximising recipient design is particularly important if the call-taker senses that the caller is, or is likely to be, resistant to the particular advice he or she is offering (Hepburn and Potter, 2011a).
(b) Balancing the needs of the PWD and the caller

In most health-related helplines, it is typically the person with the health condition themselves who is calling. However (as noted Part (i) above), most of the callers to the AND dementia helpline are carers/relatives of PWD, rather than PWDs themselves. Although the call-takers display primary engagement with the caller’s needs, they are also – appropriately – oriented to the needs of the PWD for whom the caller is concerned/responsible. One distinctive – and very skilful – aspect of the service provided by AN Direct is the way in which the call-takers ‘balance’ their engagement with the needs of the caller and the needs of the PWD under discussion. Extensive ‘balancing’ of this type is particularly evident in a substantial subset of the calls (n=53; 17%). (It will not, of course, be relevant in all calls.)

On the one hand, call-takers very commonly express concerns about callers’ wellbeing, and encourage them to “take care” or “look after themselves”, if necessary obtaining additional help or respite care. They say, for example:

• “I am very concerned about you, um, because of what it’s doing to you”
• “...one of the things I’m concerned about is your mood”
• “It sounds like, you know, with all of that going on ... you might need some help and things”
• “Please look after yourself and your sister”
• “You want to look after your own needs”
• “You need to be looking after yourself”
• “I do believe that you need a little bit of ‘me time’”
• “You need a break and a breather”
• “Oh my goodness, you certainly do need a respite”.

On the other hand, call-takers also address the physical and psychological needs of the PWD: for example, checking out the safety of their physical environment; exploring possible physical causes of confusion and psychological distress which might mimic dementia (e.g. dehydration, UTIs, drug regimes); and so on.

The call-takers very frequently encourage callers to balance the needs of the PWD (and also their other caring responsibilities) with their own needs. One said (to a caller who was feeling guilty about admitting her needs, they are also – appropriately – oriented to the needs of the PWD for whom the caller is concerned/responsible. One distinctive – and very skilful – aspect of the service provided by AN Direct is the way in which the call-takers ‘balance’ their engagement with the needs of the caller and the needs of the PWD under discussion. Extensive ‘balancing’ of this type is particularly evident in a substantial subset of the calls (n=53; 17%). (It will not, of course, be relevant in all calls.)

On the one hand, call-takers very commonly express concerns about callers’ wellbeing, and encourage them to “take care” or “look after themselves”, if necessary obtaining additional help or respite care. They say, for example:

• “I am very concerned about you, um, because of what it’s doing to you”
• “...one of the things I’m concerned about is your mood”
• “It sounds like, you know, with all of that going on ... you might need some help and things”
• “Please look after yourself and your sister”
• “You want to look after your own needs”
• “You need to be looking after yourself”
• “I do believe that you need a little bit of ‘me time’”
• “You need a break and a breather”
• “Oh my goodness, you certainly do need a respite”.

On the other hand, call-takers also address the physical and psychological needs of the PWD: for example, checking out the safety of their physical environment; exploring possible physical causes of confusion and psychological distress which might mimic dementia (e.g. dehydration, UTIs, drug regimes); and so on.

The call-takers very frequently encourage callers to balance the needs of the PWD (and also their other caring responsibilities) with their own needs. One said (to a caller who was feeling guilty about admitting her husband to a care home):

“You talk about having ‘put him away’, but you’ve also deprived yourself of a husband at home. It’s not just what has happened to him, it’s what’s happening to you. [...] You can look at it different ways, but you know, as Admiral Nurses, we often talk about the carer balancing their needs with the person with dementia. You have to do that, and that’s what you’ve had to do here.” (B6o)

Here are some more examples of call-takers explicitly encouraging callers to balance their own needs with those of others (all of the call-takers did this):

“...if you carry on like this, you’ll carry on being abused like this, you’ll carry on feeling exhausted and tearful and upset.” (A38)

“You need a break and a breather” (A77)

“I do believe that you need a little bit of ‘me time’” (A38)

“You need to be looking after yourself” (A77)

“I am very concerned about you, um, because of what it’s doing to you” (A77)

“You need to be looking after yourself” (A77)

“You want to look after your own needs” (A77)

“You need a break and a breather” (A77)

“Please look after yourself and your sister” (A77)

“Your talk about having ‘put him away’, but you’ve also deprived yourself of a husband at home. It’s not just what has happened to him, it’s what’s happening to you. [...] You can look at it different ways, but you know, as Admiral Nurses, we often talk about the carer balancing their needs with the person with dementia. You have to do that, and that’s what you’ve had to do here.” (B6o)

When talking about the needs of the PWD, rather than those the caller, one distinctive aspect of the calls was that call-takers treated the PWD as an individual with agency, not just as the source of the problem. (All of the call-takers did this.) They often invited callers to consider the issue or problem from the perspective of the PWD, considering what he or she might want or need, and how best to address this.

For example:

(Father getting up throughout the night.)

“Maybe he’s waking up and, in his reality, he’s thinking he’s left work and wondering, ‘Have I locked the door?’” (A5)

“He can’t say what he wants. He can’t get it out. And unfortunately because your mum is there, perhaps he’s trying to say something to her, trying to do something, and it’s not working so he strikes out at her.” (A35)

“There has to be a balance because you have got your son and your family etc. as well to look after. It’s what it’s doing to them, it’s pulling you in two directions. What’s it doing to you, what’s it doing to your stepfather? So it’s not just your mother’s needs and the social services.” (B42)

“I can hear it in your voice as well, the stress you know. And I-, you know the balancing of needs, I was sort of coming at that. Yes, you do have to balance all of your needs. All of you have to.” (B42 again)

“I would get on to social services. She may not want the care but you know, as a carer, you’ve got to balance what you need as well, your health thing, your health needs.” (B47)

“I think one thing you can do is try and get some time for yourself and get someone to stay with your wife.” (C3)

(Caller is crying, and says she has given up her whole life for her mother.)

“Aww, well you know [name], if you’re not managing, if you’re not coping and it’s getting too much for you both, then you have to re-look at Mum going back into the care home full-time. [...] You have to think of your own health as well. (D72)

“If you can sort of mix and match things that can better meet what your needs are, then the more success you’re going to have really. And that regular kind of support and breather for yourself – that some others can help just to take some of the pressure, and do some of the things for you.” (E2)

“You’ve got to think about your balance of life. And with two children it’s pretty time consuming, and you’re working and you’re on your own, so you’ve got a lot of responsibilities to deal with. [...] Do take care of yourself as well, make sure you get some time for yourself. (F3)
“Her view is not necessarily what everybody else is seeing. You know, it’s her view through her illness. So, you know, she’s- she is objecting to people washing her. Um, but then she doesn’t understand that she’s not washing herself perhaps or the necessity of washing herself.” (B18)

(Mother wanting to leave care home.)

“So her wish is to go home, so you know as far as she’s concerned at that time, she could go home and she doesn’t see why not. [...] She may not be able to empathise with you an, you know, your family having to go up and down the motorway. She may not realise that that is a problem for you.” (B31)

“And the thing about this feeling is it’s so big it sort of undermines your confidence in people and if she really believes you’re stealing she’s going to be, you know, she’s going to lose confidence in her relationship with you.” (C4)

(After caller complains about mother watching same thing over and over again.)

“Right, but you know every time she sees it, she’s seeing it for the first time and she clearly enjoys it.” (D9)

“She just really needs to, to get to know the carer and build up, you know, a good sort of trusting relationship with them – with the carer.” (D82)

“She’s also aware that obviously things are moving on and deteriorating and that she is not able to do what she has been able to do in the past. Um, and that vulnerability and that change can often cause those feelings and feel very isolated and very alone and quite frightened.” (E24)

“So she’ll be remembering things from the past and that’s why she’s saying she wants to be in [area of country] because that’s where she felt safe as a child.” (F20)

Helping callers to understand something of the experience of the PWD in this way may also help them to cope better with the difficult situation(s) in which they find themselves. It may also help them to retain a sense of the personhood of their loved one for as long as possible.

(c) Providing emotional support: understanding and empathy

Across the literature on telephone helplines, there is an emphasis on call-taker neutrality, together with an analysis of how this neutrality is achieved, how difficult it is to achieve, and how (often) it breaks down (e.g. Emmison and Danby, 2007; Hepburn, Wilkinson and Butler, 2014). However, the AN Direct dementia helpline is relatively unusual in that the call-takers do not strive for neutrality: rather one of its ‘hallmarks’ is the degree of understanding and empathy that is displayed by the call-takers, as part of the process of providing emotional support for callers.

One way of expressing an understanding of a caller’s situation is to say something like: “I know”; “I’m aware of how very hard it is”; “I understand that completely”; “I do understand how you feel”; “I know what you’re going through” – and the call-takers often do this. However, conversation analysts – from founder Harvey Sacks onwards – make an important distinction between claiming understanding and showing understanding (e.g. Sacks, 1995, Vol. 2: 141-2). This distinction links nicely with contemporary understandings of effective clinical empathy - as consisting not only of the ability to understand someone’s situation, perspective and feelings, but also the ability to communicate that understanding to them (Coulehan et al, 2001: 222). It is also reflected in models of empathy which focus on “the moment-to-moment communication behaviors and interactional sequences that constitute empathy in action” (Suchman et al, 1997: 678).

Utterances like “I do understand ...” claim an understanding of the caller’s situation, whereas it can be more powerfully supportive and empathetic, to show an understanding. The AND dementia helpline call-takers show understanding – and so effectively display empathy - in a wide variety of ways. These include:

- Naming how the caller is (or is likely to be) feeling
- Normalising the caller’s situation
- Offering an assessment of the caller’s situation
- Expressing sympathy or regret
- ‘Performing’ or ‘enacting’ a response - using ‘reaction tokens’
- Showing understanding by completing a caller’s utterance
- Affirming actions (and the limits of actions)
- Praising or complimenting the caller and/or the caller’s actions
- Other practices

The analysis below gives examples of each of these in turn.

Naming how the caller is (or is likely to be) feeling

One way of showing an empathetic understanding of the situation someone is in is to give a name to what they are feeling, or likely to be feeling (Pudlinski, 2005). So, for example, call-takers say things like:

- “I hear the anxiety”
- “You just feel so guilty”
- “You can really pull your hair out some days”
- “And you’re clearly concerned”
- “You must be very worried too”
- “I can hear not just the frustration but the tiredness”
- “You felt very scrutinised”
- “You just feel as though you’re fighting the whole time”
- “really quite distressing”
- “ready to collapse from the sound of things”
- “your fragile state at the moment”
- “on quite an emotional rollercoaster”
- “feeling so desperate and fraught with this situation”
- “I feel for you”
- “I understand what you’re going through”
- “I actually feel for you”
Occasionally, a call-taker even ‘voices’ the caller’s (likely) thoughts, as ‘evidence’ for how she ‘must’ be feeling. For example, in responding to a caller’s description of how her mother keeps asking the same question, over and over, one call-taker’s response is to say:

“That’s the frustrating thing for you – because you think, ‘Oh God’, you know, ‘I’ve just told you that’, but you have to respond as if she’s asked you the question for the first time”. (D65)

This kind of response also does additional ‘work’ in ‘modeling’ how carers of people with dementia ‘should’ respond, and is clearly grounded in the call-taker’s considerable experience of working with families facing dementia.

Normalising the caller’s situation

Sometimes, call-takers explicitly refer to their professional experience in order to show understanding in supporting callers. They say:

• “Because I know from my experience, that can prove, um, very difficult”
• “And sadly- from my experience, you know, you have to wait for people to even deteriorate further”.

They make reference to what they ‘often’ or ‘frequently’ encounter – thereby normalising the caller’s situation as one that is typical, common, or not unusual. They say things like:

• “That’s often the case”
• “Sadly, we hear that every day”
• “It is a common thing that we do see”
• “You’re not the first person today to say ...”
• “It’s very common for people with memory problems to become depressed”
• “It is a very, very common issue for people with infections, especially urinary infections”
• “What you’re saying is what I’m hearing quite frequently about people who don’t want to go out from their homes”
• “We often hear carers who are in the same situation, where there are relatives nearby and where they have conflict with the relatives”.

Such formulations convey the message ‘I understand this problem because I have encountered it (many times) before’.

Offering an assessment of the caller’s situation

Call-takers often show empathy through offering assessments of the situation the caller is in, such as:

• “That’s so hard on you”
• “That is hard, very hard”
• “That’s quite tough”
• “That’s really sad for you”
• “That’s one of the saddest things”
• “It’s an awful time”

• “It’s so frustrating”
• and occasionally a positive assessment, such as “That’s really nice”.

Sometimes these assessments are accompanied by a ‘tag question’ (e.g. “isn’t it?”; “haven’t you?”) – as, for example, in:

• “It’s very difficult for you, isn’t it?”
• “You’ve had quite a battle, haven’t you?”
• “It’s very frustrating, isn’t it?”
• “That’s so sad, isn’t it?”
• “There is a lot going on, isn’t there?”
• “It’s a mountain of problems to have to try and overcome, isn’t it?”
• “It’s really- it’s very dangerous for you, isn’t it?”
• and occasionally a positive one, such as “Oh that’s fabulous, isn’t it? That’s something good”.

Tag questions are used like this to acknowledge that – of course - the caller already knows how he or she is feeling about the situation (Hepburn and Potter, 2011b).

Expressing sympathy or regret

Another way of showing understanding is to express sympathy with, or regret for, the situation the caller is in (see Pudlinski, 2005). Call-takers say, for example: “I’m so sorry”; “I’m sorry you’ve got to go through so much trouble”; “I’m sorry you’re having such a hard time”; or “That’s a shame”.

Sometimes these expressions of sympathy or regret are also accompanied by an assessment, as in, for example: “Sorry. It is difficult”; or

Call-taker: It sounds terrible.
Caller: Yeah. It is terrible.
Call-taker: Yeah. I am sorry [name].

‘Performing’ or ‘enacting’ a response - using ‘reaction tokens’

A still more powerful way of showing that you understand someone’s situation is to display or enact an emotional response to it – using what conversation analysts call ‘reaction tokens’ (Wilkinson and Kitzinger, 2006). A reaction token comes across as an involuntary, visceral response to something awful, or surprising, or touching (or otherwise worthy of a reaction).

So instead of expressing sympathy by saying that they are sorry, call-takers sometimes perform sympathy by producing reaction tokens like “aaah” or “awww”. Likewise they enact surprise or dismay or horror through reaction tokens such as “Gosh”; “Goodness me”; “Oh (my) goodness”; “Oh God”; “Oh my Lord”; “Oh my word”; “Oh dear”; “Oh no”; and even through uttering gasps and groans. Sometimes a reaction token is accompanied by an assessment, which elaborates on its meaning, as in “Oh dear, that’s not very nice” or “Oh God, that’s terrible”.

• “That’s the frustrating thing for you – because you think, ‘Oh God’, you know, ‘I’ve just told you that’, but you have to respond as if she’s asked you the question for the first time”. (D65)
Perhaps because of the widespread expectation of call-taker neutrality, noted above, the use of reaction tokens is relatively rare in helpline interaction—and indeed in client-professional interaction more generally. This is another way, then, that the AND service is distinctive.

**Showing understanding by completing a caller’s utterance**

In the normal course of conversation, one person completes what they are saying and another then responds—in other words, they ‘take turns’ at talk (Sacks, Schegloff and Jefferson, 1974). Occasionally, however, someone comes in to complete another’s sentence for them: a phenomenon known as ‘collaborative completion’ (e.g. Lerner, 1996). It is usually assumed that you need to know someone well in order to be able to do this—even that it is an index of intimacy. In fact, it has been observed on telephone helplines (Wilkinson and Kitzinger, in press) —where it is a way in which a call-taker can show that she is so ‘in tune’ with the caller that she can (literally) ‘take the words out of their mouth’. Here are two examples. In the first (D71), the caller has been describing how her husband’s relative—who is in a care home— is not interested in activities any more, and sleeps most of the time, and the call-taker has just suggested that this might be another stage in her dementia. The caller says, “Well, if we felt that, perhaps we wouldn’t be quite so…”. She then pauses—and the call-taker comes in to provide (an appropriate) word to complete the caller’s sentence: “…concerned”. In this way, she shows that she understands what the caller is feeling.

In the second—more extended—example (D7), the caller has been pursuing a respite care place for his father, in order to give his mother (the main carer, herself unwell) a badly-needed break. He is frustrated by the slowness of Social Services in meeting this need:

**Caller:** And they know it’s very urgent. But last Friday, basically they said he could go into a place in [name of town].

**Call-taker:** Okay.

**Caller:** Uhm (pause) Yeah, it’s been nearly a- what? It’s a week now.

**Call-taker:** Mm. Right. Yes.

**Caller:** Well it’s four d-ays.

**Call-taker:** Yeah. Okay.

**Caller:** And (                )…

**Call-taker:** … (overlaps) an’ obviously it’s Friday today, so nothing is gonna ha- probably happen over the weekend.

**Caller:** No.

In coming in to provide the upshot of it’s being a Friday as meaning a further delay, the call-taker shows that she understands, and aligns with, the caller’s complaint about Social Services. Collaborative completions of this kind are generally quite skilled and can project a highly empathetic understanding of the caller’s concerns.

**Affirming actions (and the limits of actions)**

Call-takers also provide emotional support for callers through affirming their actions—i.e. reassuring them that they are making good decisions or acting appropriately. They say things like:

- “I think that’s a good idea”
- “That’s a good idea as well”
- “Well I think that is really the best route to go down”
- “That is the perfect thing to be doing”
- “Yes, that’s actually the right thing to do”
- “It sounds like you’re doing things exactly right”
- “What you’re doing are just the absolute right things”
- “I think you’re doing the right thing by saying no”
- “Well, I think you’ve done all the right things”
- “You’re doing the right things, you know [name], be assured of that”
- “You’re doing absolutely everything right”

Sometimes these affirmations take the form of affirming the limits of actions—i.e. reassuring the caller that they have done everything that they (reasonably) can, or that there is nothing more to be done:

- “I’m not sure if there’s anything else that you can be doing, to be honest with you [name]”
- “You sound like you’ve done everything, or you’re doing everything that can kind of support her at home at the moment”
- “And you sound like you are doing everything that anyone possibly can to try and keep things ticking over for her”
- “I think you’ve done everything you can to support her, and you’re still doing that but it is- sometimes it’s just more than one person can do”
- “You can only give what you can give. You can’t be all things to all men”.

**Praising or complimenting the caller and/or the caller’s actions**

Closely-related to affirming actions, call-takers also praise or compliment callers for what they have done, or how they have done it. They say, for instance:

- “Well done!”
- “So well done for finding that home”
- “Well done for you and your sister as well”
- “So you’ve really looked at your safety. Well done. Brilliant”
- “Excellent. That sounds good”
- “Oh that’s fabulous”
- “It does sound as though you’ve given so much thought to this”
- “You’ve done amazing, you’ve done fabulous”
- “I think you have gone away, above and beyond”.

In coming in to provide the upshot of it’s being a Friday as meaning a further delay, the call-taker shows that she understands, and aligns with, the caller’s complaint about Social Services. Collaborative completions of this kind are generally quite skilled and can project a highly empathetic understanding of the caller’s concerns.
Compliments like this have been documented on a helpline dedicated to supporting women seeking home births. The researchers (Shaw and Kitzinger, 2012) suggest that complimenting is a technique used by the call-taker to empower the caller to action. This may be particularly apparent on the AN Direct helpline when compliments are used in the present continuing tense to refer to ongoing actions (rather than in the past tense, to refer to past actions, as in the examples above). Used like this, they seem to have the force of an encouragement or exhortation to ‘keep going’:

• “It sounds as if, you know, you’re doing a great job
• “It sounds, from what you’re saying, that you’re doing an incredible job”
• “It sounds like you are doing terrific, absolutely terrific”
• “It sounds like you’re doing an amazing job of keeping them going actually”
• “You’re both doing a brilliant job”
• “You’re doing great”
• “You’re doing a great job and keep up the good work”
• “Oh you’re amazing. You really are, to take all of this and cope with all of this.”
• “You’re the silver bullet, you and the family, you’re the silver bullet”
• “You’re strong, okay”.

Other practices
We identified (at least) six other practices for providing emotional support to callers through showing understanding and/or empathy. There were fewer examples of each of these in the data set. These additional practices are simply listed below, with examples but no further discussion. (This list is probably not exhaustive.)

Thanking the caller:
• “Thank you for caring for her”.
• “Thank you so much that you are there for her”.

Validating feelings:
Caller: “It is quite a difficult one”. Call-taker: “Of course it is”.
Caller: “I wasn’t going to go because I was exhausted”. Call-taker: “I’m sure, yes”.
Caller: “It’s just hard work”. Call-taker: “Right. Yes, of course. Of course”.

Challenging self-blame:
• “This is not your fault”
• “You have nothing to be ashamed about”

Appealing to ‘the way things are’:
• “That’s what happens. It’s completely understandable.”
• “Even though you shouldn’t feel guilty, you will do. I mean it’s- you know it’s just a fact of life really.”
• “It’s the fault of circumstance, rather than you as an individual.”
• “I think, you know, there comes a point regardless of illness that enough is enough.”

In sum, then, this section has shown that AND call-takers are far from neutral recipients of callers’ problems. They do a great deal of ‘work’ to show that they understand and empathise with callers, thereby providing a high level of emotional support.

Part (iii) Call-taker practice & other points of interest

This section will offer some final examples of, and reflections on, what constitutes good call-handling practice (and analysis of a very few instances of less good practice). It will also raise some additional points of interest that have not been addressed elsewhere in this report.

The expert coders were asked to ‘flag up’ calls they considered to be handled ‘particularly well’, or ‘well’, and calls they considered to be ‘not handled well’, with brief explanatory notes on each. (Both coders have considerable experience of evaluating professional interactions in this way.)

Across the data set, 71 calls (23%) were deemed to have been handled particularly well; 116 calls (38%) were deemed to have been handled well; and only 9 calls (3%) were deemed not well handled.

Calls deemed to be handled particularly well were identified for all six of the call-takers in the study, and calls deemed not handled well were distributed across the three call-takers who provided the largest number of calls.

Central to good practice was providing a mix of practical advice and emotional support; balancing of the needs of caller and PWD; and displaying a high degree of understanding and empathy - as identified and analysed in Part (ii) of the Results section above.
In addition, the coders’ notes identified the following among the instances of good practice:

- Allowing caller sufficient time to explain concerns at their own pace, without hurrying them along or cutting them off
- Addressing all of their concerns in turn
- Redirecting call effectively and sensitively when caller goes off topic
- Seeking information/advice from colleagues when necessary
- Offering appropriate follow-ups

Each of these was widespread across the data set.

An analysis of the nine calls that were less well handled identified three particular difficulties:

(i) Apparent misalignment between caller and call-taker (where the call-taker does not seem to get the ‘point’ of the call, and/or the caller does not get the help he or she is seeking).

(ii) Allowing callers ‘free rein’ to talk at length, without focusing the conversation.

(iii) Difficulties in dealing with callers who are resistant to advice.

The last of these has been noted particularly frequently in studies of advice-giving on telephone helplines (e.g. Butler et al, 2010; Emmison and Firth, 2012; Hepburn and Potter, 2011a).

Other points of interest in the calls include:

(i) A significant subset in which domestic abuse is described (handled sensitively by the call-takers, with appropriate reference to safeguarding).

(ii) A concern quite often expressed by the call-takers that they are NOT helping the caller, or that they are being insufficiently helpful. This is partly underpinned by the fact that it was often not possible to refer callers to an Admiral Nurse in their local area (where this was what was wanted or needed), because there are relatively few Admiral Nurses working in the community.

(iii) Nowhere in the calls is there any reference to (let alone discussion of) end-of-life issues - including advance care planning and decision-making for the end of life. The calls are primarily focused on the present, rather than the future. Insofar as the future is ever envisaged, there is a strong presumption in favour of continued treatment and the sustaining of life. Advance Decisions to Refuse Treatment are never mentioned – although these could potentially be completed by someone in the early stages of dementia. Indeed, very few calls even address future loss of mental capacity, apart from a few references to Lasting Powers of Attorney.

Concluding Comments

This study/evaluation of the Admiral Nursing Direct dementia helpline has provided a ‘snapshot’ of the service and a more in-depth analysis of call-handling practices. It has shown that most calls to the helpline are first calls from someone caring for a person with dementia, and that the most typical caller is a daughter caring for a mother in the mother’s own home.

It has shown that call-handling entails providing a mix of advice and support, including practical, emotional and informational support. Call-takers typically balance the needs of the caller and the PWD; and offer the caller substantial emotional support, particularly understanding and empathy.

From the analysis of call-taker practice reported here, it is clear that the helpline service is uniformly excellent — and that this is so across all of the call-takers included in the study. The extensive praise and thanks from callers exemplified in Appendix 2) also attests to this.

It is also clear that the service rests on a very substantial base of knowledge and experience on the part of the call-takers. The range of issues they are able to address, and the skill with which they handle often very lengthy and complex calls attests to this. The wide variety of ways in which call-takers deploy their skills and experience to provide emotional support for callers is particularly impressive.

It is difficult to identify any substantive areas in need of improvement.

Dementia UK may wish to reflect on just two points:

(i) The implications of displaying such a high degree of empathy, with such frequency: on the one hand, it may underpin caller satisfaction with the service; on the other, it may be one of the reasons why many calls are so protracted.

(ii) The absence of discussion of end-of-life issues, and whether this might be addressed: on the one hand, callers do not raise these issues (they are preoccupied with the present, rather than thinking about the future); on the other, call-takers could potentially provide a valuable service in encouraging them to plan ahead.
References


Coulehan, J.L, Platt, F.W., Egener, B. et al. (2001) ‘Let me see if I have this right…’: Words that build empathy. Annals of Internal Medicine 135(3): 221-227


Biographical Note

Sue Wilkinson is a Chartered Psychologist and Honorary Professor in the Department of Sociology, University of York. She is also an Emeritus Professor at Loughborough University, where she co-founded the Helpline Research Unit. Her recent research projects include studies of helplines run by the Fibromyalgia Association, Unlock and Compassion in Dying. She is also co-founder and Chair of a charity providing support, training and research around Advance Decisions to Refuse Treatment (ADA: Advance Decisions Assistance).

Acknowledgements

I would like to thank Karen Harrison-Dening and Ian Weatherhead at Dementia UK for their enthusiasm and support for the research, and the six Admiral Nursing Direct dementia helpline call-takers for recording their calls. Many thanks also to Kathrina Connabeer and Ann Doehring for their meticulous coding and their engagement with this research more generally.
## Appendix 1

‘AN Direct’ helpline calls final coding key

### Sheet 1: summary/demographic info

1. Status of call (i)
   - Call taken as comes in
   - Call-back from message on ansaphone

2. Status of call (ii)
   - First call
   - Subsequent call
   - Can’t tell

3. Status of caller
   - Person with dementia (PWD) (or worried about having dementia)
   - Carer of PWD – relative/friend (log relationship: partner; child; sibling; other relative; friend; other)
   - Other concerned relative/friend (log relationship: partner; child; sibling; other relative; friend; other)
   - Professional
   - Mixed professional/personal

3a. Sex of PWD (whether caller, or PWD under discussion)

4. Where does PWD live (whether caller, or PWD under discussion)?
   - Own home
   - alone; or with partner/someone else?
   - Caller’s home
   - Institution (hospital or care home)

5. Banner headline for ‘problem presentation’ (separate Word doc)
   List up to 3; put main (if there is a main) in **bold**

6. Does call contain complaint(s)?

7. Does caller offer donation?

8. Praise/thanks offered by caller (separate Word doc for all ‘extended’ instances)

8a. No thanks offered (note if problematic call)

### Sheets 2&3: call-handling

9. Key aspects of caller response:
   - Dealing with PWD
   - Dealing with effect on caller/carer (typically primary client of helpline)
   - ‘Balancing’ of both
   - (Word doc: note code nos of calls & brief details - where ‘balancing’ of this is partic. clear)

9a. Suggesting strategies for dealing with PWD:
   - practical (eg check safety)
   - psychological (eg how to handle)

9b. Dealing with effect on caller: offering various kinds of support:
   - practical
   - emotional
   - informational

9c. More detail on informational support:
   - providing info about services available (one column, code for type of service)
   - dementia generally (D)
   - Admiral Nurses in particular (AN)
   - other services for PWDs (S-D)
   - other services for carers (S-C)
   - legal & financial SERVICES (L&F)
   - other (O)

10. Advice-giving?
    +A-accepted; +R-rejected

10a. Areas/types of advice:
    - Health/medication
    - Living situation
    - Dealing with care system
    - Diagnosis
    - Sleeping
    - Self-care
    - Community
    - Other

11. ‘Support/care’-giving?
    +A if advice follows
11a. Types of ‘support/care’:
   • Empathy
   • Concern/care
   • Praising/complimenting
   • Mixed
   • Other

(+ Word doc with examples of best instances; + different practices used: e.g. for empathy, could include collaborative completions, reaction tokens (oaah), ‘you must feel x’, etc.)

12. Other points of interest (Word doc)
   e.g. Call-taker orientation to ‘helping’ (or not); end-of-life issues; domestic abuse. Others?

13. Info to be sent?
   (+A if related to advice)

14. Call back offered?

15. Note code nos of calls handled partic. well or less well
   (Word doc for examples of good practice and less good practice)

### Appendix 2

<table>
<thead>
<tr>
<th>Call ID</th>
<th>Praise/Thanks by Caller - Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>AND A1</td>
<td>“Thank you very much indeed. That’s very, very helpful.”</td>
</tr>
<tr>
<td></td>
<td>“Thank you for your help.”</td>
</tr>
<tr>
<td>AND A2</td>
<td>“I’ve used you before on several occasions and you’ve always, always been fantastic.”</td>
</tr>
<tr>
<td></td>
<td>“People like you- people like yourself are the ones who support me, actually.”</td>
</tr>
<tr>
<td></td>
<td>“So, er, I’m always extremely grateful to you, so anything I can do.”</td>
</tr>
<tr>
<td></td>
<td>“Thank you. Thanks a lot for that.”</td>
</tr>
<tr>
<td>AND A9</td>
<td>“Thank you very much. I wish you could come in my pocket with me.”</td>
</tr>
<tr>
<td></td>
<td>“Well, thank you very much for your help.”</td>
</tr>
<tr>
<td>AND A24</td>
<td>“Okay, well, thank you for your time. Thank you. I really appreciate that. Thank you.”</td>
</tr>
<tr>
<td>AND A28</td>
<td>“Oh, great. I’m glad I rung you. Thank you very much.”</td>
</tr>
<tr>
<td></td>
<td>“Thank you ever so much.”</td>
</tr>
<tr>
<td></td>
<td>“I’ll ring you again.”</td>
</tr>
<tr>
<td>AND 30</td>
<td>“Thank you for calling me back.”</td>
</tr>
<tr>
<td></td>
<td>“No, that’s great. Thank you very much for your time.”</td>
</tr>
<tr>
<td></td>
<td>“Yeah lovely. Thank you.”</td>
</tr>
<tr>
<td></td>
<td>“Lovely, that would be great.”</td>
</tr>
<tr>
<td></td>
<td>“Cheers then. Well, thanks very much for your time and your help.”</td>
</tr>
<tr>
<td></td>
<td>“Thank you.”</td>
</tr>
<tr>
<td>AND 34</td>
<td>“Brilliant, I hadn’t even thought of that.”</td>
</tr>
<tr>
<td></td>
<td>“If there is anything that might be useful, I’d be very grateful for.”</td>
</tr>
<tr>
<td></td>
<td>“Oh, that’s brilliant.”</td>
</tr>
<tr>
<td></td>
<td>“Thank you very, very much.”</td>
</tr>
<tr>
<td></td>
<td>“Thank you.”</td>
</tr>
<tr>
<td>AND 35</td>
<td>“Yes, that’d be very helpful.”</td>
</tr>
<tr>
<td></td>
<td>“That would be helpful.”</td>
</tr>
<tr>
<td></td>
<td>“Right, well, thanks ever so much for that. That was very helpful.”</td>
</tr>
<tr>
<td></td>
<td>“Thanks ever so much for that.”</td>
</tr>
<tr>
<td></td>
<td>“Thank you very much indeed.”</td>
</tr>
<tr>
<td>AND 39</td>
<td>“Okay. That’s brilliant.”</td>
</tr>
<tr>
<td></td>
<td>“That’s lovely. Thank you so much indeed for everything.”</td>
</tr>
<tr>
<td></td>
<td>“Thank you so much.”</td>
</tr>
<tr>
<td></td>
<td>“Thank you very much indeed for your help.”</td>
</tr>
<tr>
<td></td>
<td>“Okay. Thank you so much indeed. Like I said, that is lovely. Thank you.”</td>
</tr>
<tr>
<td>AND 41</td>
<td>“Oh, thank you very much.”</td>
</tr>
<tr>
<td></td>
<td>“That’s really kind.”</td>
</tr>
<tr>
<td></td>
<td>“Thank you. Thank you very much.”</td>
</tr>
<tr>
<td></td>
<td>“Oh right that’s so handy.”</td>
</tr>
<tr>
<td></td>
<td>“Urm, that really, really helps to know that people can help us.”</td>
</tr>
<tr>
<td></td>
<td>“Thank you. I really appreciate it very much.”</td>
</tr>
</tbody>
</table>
|AND 31| “I really needed some guidance, which you’ve given me and thank you for that.”  
“That’s very useful.”  
“Thank you.”  
“Very useful.” |
|---|---|
|AND 52| “Thank you, and I’m really appreciative.”  
“So thank you, I can’t thank you enough for being so prompt and coming back to me. Thank you.”  
“That’s fantastic.”  
“Thank you.” |
|AND 57| “Well thank you so much for ringing back so quick.”  
“I’m very grateful you’re there.”  
“Thank you so much.”  
“Oh, bless you for being at the end of the phone. I really appreciate it.”  
“Thank you so much, I really appreciate it.”  
“Thank you so much.” |
|AND 59| “Well it’s great to have a chat. It’s been very helpful.”  
“Well it’s been very helpful. It’s good to know that it’s happening to other people, you know, other carers are sort of having similar issues.”  
“Okay well thank you very much. Thanks for listening, thank you.” |
|AND A78| “Thank you very much. anyway. Thanks very much, indeed for all your help.”  
“You’ve been wonderful.”  
“Anyway that’s really kind of you, I’m grateful.” |
|AND A80| “Thank you very much. So, um, well that’s been very helpful. Thank you for, er, for ringing back. That’s really good. Thank you ever so much for your time. That’s, er, been very helpful. Thank you very much.” |
|AND B13| “That would be brilliant.”  
“That would be fantastic, yes. No I think that’s- that’s brilliant because I’m at an end where I don’t really know where to look anymore. Thank you so much for your help.”  
“I can happily go on the recording that I think you’re brilliant, so there you go.”  
“Thank you very much.” |
|AND B30 & 31| “Thank you, thank you for all the time you’ve spent.”  
“Yeah, thank you so much. Thank you so much.”  
“Thank you for listening.”  
“Thank you for all your valued support.”  
“And also thank you very much for the ideas.” |
|AND B35| “Thank you so much for ringing back.”  
“Well it’s very nice speaking to you, anyway. Thanks very much.”  
“Thanks very much, indeed for all your help.”  
“You’ve been wonderful.”  
“Anyway that’s really kind of you, I’m grateful.” |
|AND B38| “Oh well I’m glad somebody understands how I feel.”  
“You’ve been an absolute bliss to talk to. “Thank you very much. It’s just made me realise that I’m not being over-reactive.” “Thank you very much. You’ve been wonderful, thank you.” |
|AND B39| “Thank you very much, lovely. Thanks a lot then, thank you.” |
|AND B45| “That would be fab, thanks”  
“The advice you’ve given me, you know, the advice you’ve given me has been brilliant actually. It’s sort of reassured me that we’re doing okay and potentially what other options there are.”  
“That’s been really helpful, thanks so much [name].”  
“Thanks so much.”  
“Thank you, thank you.” |
|AND B50| “That would be brilliant.”  
“Excellent, thank you.”  
“Thank you [name]. Thank you so much. That was really helpful.”  
“Thanks a lot.” |
|AND B56| “That would be brilliant.”  
“You’ve helped me a lot.”  
“All right, then. Thank you very much.”  
“Thank you.” |
|AND B60| “Thank you very much, anyway.”  
“You’ve helped me a lot.”  
“All right, then. Thank you very much.”  
“Thank you.” |
|AND C13| “That would be excellent, thank you.”  
“Excellent, thank you.”  
“Thank you [name]. Thank you so much. That was really helpful.”  
“Thanks a lot.” |
|AND C16| “Oh that would be brilliant.”  
“Well you are helping, as it happens. You are helping. I mean, this technological bit that you are- I didn’t even know that existed, and that could be helpful.”  
“You have been helpful, thanks.”  
“Yeah thanks for your help. I really appreciate it, thanks.” |
|AND C19| “Okay, that’s brilliant.”  
“Yeah, smashing. That’s brilliant.”  
“Okay, thank you very much for your help.”  
“Alright, thank you very much, thanks.” |
| AND C20 | “Thanks for listening.”
| | “No that’s fine. No, that’s fine. I’ve had plenty much of your time. Well thank you very much [name]. It’s been really helpful.”
| | “Will do. Thanks for your help.”
| AND C21 | Okay, Brilliant. Alright. It’s been a good help. Thank you very much.”
| | “ Brilliant. Thank you very much. Alright.”
| AND D34 | “That would be absolutely brilliant. Thanks ever so much for your time.”
| | “That’s it. You’ve been most helpful.”
| AND D41 | “Oh that’s ever so kind.”
| | “Thank you. That’s brilliant.”
| | “Thank you ever so much.”
| AND D44 | “Thanks for calling me back.”
| | “Oh that’s a good idea. That’s a brilliant idea.”
| | “Yeah. Oh thank you, that’s a really helpful bit of advice. I haven’t even thought about something like that.”
| | “Thanks very much.”
| | “You’ve been a really big help, thank you.”
| AND D52 | “This is my problem. I don’t know you. But you have absolutely understood the whole problem. In 5 minutes.”
| | “Thank you so much for your call.”
| | “I do appreciate it.”
| | “Thank you so much for your time.”
| ADD D88 | “Yeah I’m glad that I’ve spoken to you now. Yeah, you’ve given me a lot of helpful advice there.”
| | “Thank you so much for. Thank you so much for calling.”
| | “Thank you very much.”
| AND D61 | (CLR) “Well (laughs) I just really wanted to ring you up and thank you for being so kind.”
| | (laughs) (CLT) “Oh (laughs) that’s very kind of you.” (CLR) “So you can record that”
| | (both laugh).
| AND D68 | “So I have to remember at the end of the conversation to say how lovely and helpful you are, so that gets recorded as well.” (laughs)
| AND D75 | “Yes that’s, that’s been – you’ve been – a great help and thank you.”
| AND D78 | “No, I think you’ve been very helpful. Thank you very much for your time, and thank you for phoning me twice.” (laughs)
| AND D88 | “Thank you very much for your help. It’s been invaluable.”
| AND E2 | “Yes, that’s great. That’s really great. Your suggestions have been brilliant.”
| | “It’s been great that you obviously understand the situation, it’s really good to talk to you about that.”
| | “Thank you so much [name].”
| | “Thank you. It’s really helped to talk to you, it really has.”
| | “Thanks [name]. Thanks very much.”
| AND E4 | “I will. Thank you very much.”
| | “Yeah, thank you very much.”
| | “Oh, you’ve been phenomenally helpful. Thank you so much.”
| | “And thanks a million. I never expected to- you to call back so quickly and you’ve been really, really helpful.”
| | “That’s brilliant.”
| | “Thanks very, very much.”
| AND E7 | “That’s great. Will thank you ever so much for your help this afternoon, that’s been marvellous.”
| | “Oh, great, that you ever so much for that. Thank you ever so much.”
| | “That’s lovely. Thank you for your time today, I do appreciate it.”
| AND E9 | “You’ve talked to me for an awful long time, and you’re very good.”
| | “Thank you very much.”
| | “Thank you so much for being so kind as well, to all my trouble.”
| | “Okay. Thank you very much.”
| | “And you have helped me, and there is a light in the wilderness. There is a light.”
| | “Thank you very much, you have been very good to me and thank you very much, you’ve brought me back to my senses.”
| | “I know. Bless you and thank you very much.”
| | “I don’t want to let you go.”
| | “Thank you [name], thank you very much.”
| AND E14 | “Good point, well that makes sense. Well thank you so much for your time, thank you so much for all your help here. I’m going to get back to the GP immediately and let them know. I really appreciate all the time you have spent with me and I will let my father know today.”
| | “Like I say, I really appreciate it. Thanks for your time sir.”
| AND E19 | “Thank you for your help.”
| | “That is superb, thank you very much for your help. That’s very, very kind.”
| | “Lovely, thanks very much indeed.”
| AND E23 | “Yes, I’m really feeling that I love you.”
| | “Do you have a tick box anywhere so I can say how helpful you were?”
| | “Hold on your taping me. This gentleman was absolutely marvellous, I’m so glad I phoned, I’m so glad I talked to you. You have no idea.”
| | “Ten stars out of five.”
| AND E24 | “Great, that’s very helpful.”
| | “You have really helped me, yes.” You have been a great help to me you know, because I was feeling so desperate with some of the- not necessarily to tell me what to do but just someone to understand what I’m saying.”
“Yes, I know. Um, I mean that’s brilliant, thanks for all of the advice that’s fantastic.”
“Right, right. Oh that’s brilliant, well thanks for giving us all that information Ian, that’s absolutely fantastic.”
“Fantastic, that’s brilliant [name], absolutely fab. Thanks for all of your help, that’s brilliant.”
“Yeah that’s brilliant, thanks a lot.”

“Very good. Okay, that’s great. I think, I think- yeah, that’s perfect now, thank you so much for coming back to me.”
“Brilliant, thank you so much.”

“Oh that would be brilliant definitely.”
“Brilliant that’s absolutely brilliant.”
“Oh that’s brilliant.”
“That’s absolutely brilliant thank you very much.”

“Brill. I’ll give it a stab.”
“That’s brilliant. Thank you very much for now.”
“Thanks very much for your help.”

“Yeah. That sounds really good. Well that’s great. Well thank you very much.”
“Yes, thank you.”
“Yes. Brilliant.”
“Alright. Thanks ever so much for your help.”
“That’s lovely. Thank you. Thanks.”

“Okay, well that’s, you’ve given me a fabulous amount of information, so I feel like I’ve got some really influence having some idea of what I’m talking about.”
“So thank you very much for that.”
“Excellent.”
“Lovely. What a lovely service. Thank you very much.”
“Thanks very much.”

“Brilliant. Thank you.”
“Brilliant. Well thank you very much for your help. I appreciate that.”
“That would be great.”
“That’s great. Thank you so much for your help. It’s given me a little bit of good knowledge and a little bit of confidence going forward. So I really appreciate your time.”
“Thanks.”
The Admiral Nursing Direct dementia helpline is for family or professional carers of someone with dementia, people dealing with a diagnosis of dementia, and those worried about their memory or the memory of a loved one.

Call 0800 888 6678 or email direct@dementiauk.org
Open seven days a week 9:00 - 17:00
Also open on Wednesday and Thursday evenings 18:00 - 21:00