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Why are relatives of care home residents reluctant to 'rock the boat'? Is there a culture of acceptance?

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Working with Older People

Why are relatives of care home residents reluctant to 'rock the boat'? Is there a culture of acceptance?

Abstract

Purpose - The purpose of this paper is to explore whether relatives of care home residents are best placed to act as 'champions' or advocates for their family members, as is often the expectation.

Design/methodology/approach - Focus groups and interviews were conducted with 25 relatives of residents in four care homes for older people in the South East of England. Two rounds of focus groups were held in each participating care home: the first was to discuss any issues arising from the care received, or concerns about the home itself; the second was to enable a deeper exploration of the key themes that arose from the first round and explore why relatives, in this case, failed to complain.

Findings - Thematic analysis revealed a complex range of emotions experienced by relatives that contributed to a conflict between what they believed to be the correct response and how they behaved in reality, which led to a culture of acceptance. Analysis revealed some relatives were reluctant to 'interfere' for fear of possible negative repercussions, thus they downplayed issues in an attempt not to 'rock the boat'.

Originality/value - This paper discusses the flaws in the policy emphasis on personalisation and the reliance on family members as advocates, and concludes with suggestions on how care homes may foster an environment where relatives, and indeed residents, feel comfortable to raise issues and concerns.

Key words

Care homes, relatives, family members, complaints, advocacy, focus groups.

Introduction

Care home residents are an increasingly frail population, experiencing multiple comorbidities including cognitive impairment (British Geriatrics Society (BGS), 2011). This makes them a very vulnerable part of the population, highly dependent on health and social care services, often with reduced capacity to champion their own rights with service providers and commissioners. Family carers are often assumed to be appropriate advocates for people receiving services. Indeed, where the cared-for person lacks capacity, relatives often act as personal consultees, making best-interest decisions on their family member's behalf (Mental Capacity Act, 2005). Family member views are also now incorporated into all aspects of Care Quality Commission (CQC) inspections, and there is a specific section in the regulation guidance asking whether relatives are encouraged to voice concerns or complaints regarding the provision of care (CQC, 2015).

However, there is growing evidence which indicates that (unpaid) family carers may not always be the most suitable champions, due to their overlapping and often conflicting caring roles (Keywood, 2003). A recent report by the CQC noted that many providers reported receiving five or fewer complaints over a 12-month period (CQC, 2014), and many inspectors felt they did not have enough evidence to ascertain how well complaints were being handled within the sector. This does not fit with the negative feedback being reported on websites (CQC, 2014), and raises concerns that issues are not being brought to the attention of care home managers through formal complaints procedures. Another CQC report examining the willingness of the general public to report concerns with health and social care services found that only 19 per cent of health and social care users had themselves voiced a concern over the past 12 months, and those who had were largely unhappy with how it had been handled. Over half said that they had not received a satisfactory response or that their concern was not welcomed, and a third said that they were not treated respectfully by

1
2
3 those dealing with the complaint (CQC, 2013). The biggest barrier to raising complaints was the
4
5 reluctance to appear as a troublemaker, while 25 per cent of people felt complaining would not
6
7 actually improve anything, and another 11 per cent felt that it would actually lead to the care getting
8
9 worse.

10
11 Many of the barriers to complaining highlighted by CQC are supported by other research. Katz *et al.*
12
13 (2013) noted that many people seemed to have low expectations of care homes. She found that
14
15 relatives seemed to accept the inevitability of shortcomings in the home. Graneheim *et al.* (2014)
16
17 also found that family members would make excuses when they experienced poor quality care,
18
19 often blaming poor education or lack of staff, or putting it down to an isolated incident. Many
20
21 people see moving into a care home as a last resort and have negative perceptions of care homes,
22
23 either based on personal experience or media portrayal (Davies and Nolan, 2003). This is supported
24
25 by a recent report by the Older People's Commissioner for Wales who 'identified a culture of
26
27 acceptance in which older people simply "made do"' and did not expect anything more than an
28
29 adequate quality of life in a care home' (Older People's Commissioner for Wales, 2014, p. 47).
30
31
32

33
34 The literature on consumer complaining highlights the cognitive and affective effort that goes into
35
36 making a complaint, as well as the physical time and procedural effort it requires (Lu *et al.*, 2015).

37
38 Customers are less likely to complain about a dissatisfactory experience if the complaining requires a
39
40 significant amount of energy and effort (Gursoy *et al.*, 2003) and less effort is likely to be undertaken
41
42 if the individual is in a negative emotional state (Lu *et al.*, 2015). In a care home context, although
43
44 family members are no longer the main carers for the cared-for person, they often reported similar
45
46 feelings of distress and burden to those providing care at home (Sury *et al.*, 2013) and experienced
47
48 continuing emotional upset (Ryan and Scullion, 2000). This emotional effect is likely to affect their
49
50 willingness and ability to raise complaints.
51
52

53
54 Whilst there is a growing awareness of, and research into, the issues around voicing complaints in
55
56 health and social care, there is little looking specifically at care homes. This paper reports on focus
57
58
59
60

1
2
3 groups and interviews with unpaid family carers of care home residents, exploring their experiences
4
5 and views on raising complaints.
6
7
8

9 **Methods**

10 ***The sample***

11
12 During 2013, family (unpaid) carers of permanent residents living in four care homes for older adults
13
14 in one local authority region in England were invited to take part in the research. These focus groups
15
16 and interviews formed part of a wider feasibility study about the quality of life of residents in care
17
18 homes for older adults (Towers *et al.*, 2016).
19
20

21
22 Two of the homes were registered for nursing and run by a large provider; the other two were
23
24 homes without nursing (residential homes) and were owned by a local independent provider. Where
25
26 the homes had contact details for them, all family members and carers of residents living in the
27
28 homes were invited to take part in focus groups. Due to data protection, we could not contact the
29
30 consultees directly so the care home manager sent recruitment packs out on our behalf. It was not
31
32 possible for the homes to tell us how many packs they had sent out because some were sent by
33
34 post, others were handed to carers during visits, and logs were not kept. Therefore, similar to
35
36 Faulkner *et al.* (2006), we were not able to calculate the response rates or comment on the
37
38 representativeness of our sample. The aim was to recruit between six to eight participants per focus
39
40 group, following the best-practice guidelines outlined in Ritchie and Lewis (2003), and this was
41
42 mostly achieved.
43
44

45
46 25 unpaid carers took part in the focus groups at time one, reducing to 22 at time two. Each focus
47
48 group contained between five and eight participants: each with a mixture of males and females. The
49
50 sample included three spouses (all husbands), 15 adult children (13 daughters and two sons), three
51
52 daughters-in-law, two sons-in-law, one grandson, one niece and two friends (who were also
53
54 neighbours). During the focus groups, it became clear that the roles and experiences of the two
55
56
57
58
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60

1
2
3 friends were very different from those of the family members, and for this reason it was decided
4
5 that the two friends should be excluded from the analysis.
6
7

8 All participants described themselves as the main or shared paid or unpaid care-giver when the
9
10 cared-for person lived at home. All spouses and three offspring had lived with the cared-for person
11
12 prior to them entering the care home. Over 50 per cent reported previously giving over 20 hours of
13
14 care a week, and two participants even stated giving over 50 hours per week. Over half of the
15
16 sample reported still being in paid work.
17
18

19 ***Data Collection***

20 Focus groups were chosen as the method of data collection in order to elicit a range of perspectives
21
22 and to discover which issues were most relevant to the group. One focus group per home was
23
24 conducted, at two time points, three months apart. The focus groups took place in a suitable quiet
25
26 room in the home, and lasted between 60 and 120 minutes. No staff or residents were present, nor
27
28 could they hear the discussions. Two researchers conducted the focus groups: one led and the other
29
30 facilitated.
31
32
33
34

35 The topic guide was used flexibly, allowing interesting topics to be discussed in more depth. Two
36
37 rounds of focus groups were held in each participating care homes. The topics in the first round
38
39 were broad to enable participants to debate what they felt constituted a good quality of life for a
40
41 resident of a care home. This also gave them the opportunity to discuss any issues arising from the
42
43 care that their relative was receiving, or concerns about the home itself. These topics included: their
44
45 feelings during the process of moving their relative into a home; their opinion of the quality of care
46
47 that their relative received; and factors they viewed as crucial for ensuring a good quality of life for
48
49 their relative. The second round used a new topic guide, designed to explore the issues that were
50
51 most pertinent to the participants in the first round. This paper focuses on the issues that were
52
53 identified in time one and explored further in time two: how relatives felt about broaching with the
54
55 home any issues, desired changes, or complaints they had.
56
57
58
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Analysis

Interviews and focus groups were audio recorded and transcribed verbatim, and data were analysed thematically using a general inductive approach to allow the development of a framework using the reported experiences and processes underlying the raw qualitative data (Thomas, 2006). Two researchers fully familiarised themselves with the data and agreed on an overall coding frame based on the topic guide and the emerging overarching themes (through cross-checking each other's transcripts to validate the credibility of the coding applied) The computer software package NVivo was used to further organise the data and support the analysis by enabling both researchers to combine their transcripts and identify common sub-themes within the overarching themes identified. Two researchers completed the analysis, and conclusions were verified and affirmed through discussions with the wider research team.

Findings

Overall, all focus groups expressed similar feelings towards raising complaints with the care home, and gave similar reasons not to. This is presented below.

Relatives views of complaining

Several participants raised the subject of complaining, unprompted, and argued that it was important to complain when issues arose. One person said he felt a duty to the resident to address any problems with their care, since this is something they might be unable to do themselves. Others expressed concern for residents who did not have a family member to look out for them in this way. Participants felt that staff needed to be made aware of problems so that they could learn from them and reduce the likelihood of them happening again:

Female relative 1: ...maybe it's something that should be spoken about to stop anybody else being in the same situation.

1
2
3 *Female relative 2: I think [care home manager] would be very pleased to hear*
4
5 *about it...because she tries so hard.*
6
7

8 *Female relative 1: And she would know that you're not criticising her or one*
9
10 *of the nurses.*
11

12
13 *Female relative 2: Yeah, and it might be a learning opportunity, mightn't it.*
14
15

16 (Focus Group, Time 2)
17

18
19 The speakers in this case seemed positive about approaching the care home manager with
20
21 problems, with a view that she would appreciate the feedback. Two other female participants with
22
23 relatives in the same home agreed, and in fact similar views were found in a different focus group:
24

25
26 *I don't see it as complaining. I see it as you're drawing someone else's attention*
27
28 *to something that you're thinking about.* (Female speaker, Time 2, Focus Group).
29
30

31 However, despite an apparent willingness amongst the groups to raise issues and a sense that it was
32
33 their duty and important for the 'greater good', a dissonance emerged between relatives' attitudes
34
35 and actions when encountering specific problems relating to their own family member. When
36
37 directly asked how they dealt with the specific issues raised, it became clear that they had not said
38
39 anything to staff or management about their concerns.
40
41

42
43 *Q: So have you said anything to the staff?*
44

45
46 *FS2: No.*
47

48
49 *Q: Is there a reason?*
50

51
52 *FS2: I'm just so grateful to them...and I just don't want to hurt anybody's*
53
54 *feelings.....she does her art, she's never done art in her life but she's in there*
55
56 *painting, I'm just so grateful.*
57
58
59
60

1
2
3 In fact, the daughter of one care home resident noted how, as a relative, you do conform to a role.
4

5 She stated:
6
7

8 *I think it goes back to the whole, you slot into your sort of pupil role and you*
9
10 *don't want to say anything in case you're picked on or your relative is picked on.*
11
12 *It's that sort of feeling of insecurity. (Female speaker, Time 2, Focus Group).*
13
14

15 In exploring this dissonance, several interlinked themes emerged that suggested why relatives may
16 not complain. These themes are now discussed.
17
18

19 ***Past experiences have led to low expectations***

20 During conversations about complaining to a care home, relatives described previous situations
21 when they had complained about an instance of poor care but the complaint had been ignored or
22 dismissed by staff and/or management.
23
24
25
26
27

28
29 *Accidents happen but it'd be nice if someone had said, 'Oh dear', and listened to*
30
31 *me about the fact that it just got put in her drawer. (Female speaker, Time 2,*
32
33 *Focus Group).*
34
35
36

37 **Low expectations and limited alternatives**

38 There was also a general sense amongst relatives that better care was not necessarily possible. 'They
39 do their best' was repeatedly mentioned as a reason for not complaining about issues, as though it
40 was not possible to expect better care. There was a widely-held belief across the groups that care
41 homes were not desirable places to live in, and given the choice they would not want to be in one
42 themselves. This was illustrated by comments such as 'I think if the truth be known no one would
43 want to be in a nursing home.' (Female speaker, Time 1, Focus Group), and 'when you see them all
44 sitting round a room you think what a horrendous place, the most awful place on the planet.'
45
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52

53 (Female speaker, Time 2, Focus Group).
54
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1
2
3 Many participants were also aware of the negative press surrounding care homes, which affected
4
5 how they felt towards their relative's care home:
6
7

8 *It's hard initially to be trusting....I suppose partly because there tends to be lots of*
9
10 *bad stories about nursing home care. (Female speaker, Time 2, Focus Group).*
11

12
13 In addition to this, many participants had first-hand experience of other care homes, which they had
14
15 found to be largely unsatisfactory. One participant explained why one of the homes her mother had
16
17 briefly stayed in was 'dreadful':
18
19

20 *I went in and they had the Teletubbies on to entertain them and I thought how*
21
22 *degrading. And it stank of urine and the carers weren't very nice. (Female*
23
24 *Speaker, Time 1, Telephone Interview).*
25
26

27
28 The negative experiences of many participants may have led them to see the current home more
29
30 favourably, relative to other, worse, homes.
31

32 In addition, family members were also aware that other options to a care home were limited:
33
34

35 *But there would be no alternative. If nursing homes weren't around then it would*
36
37 *be hospital, and the hospital haven't got the beds. (Male speaker, Time 1, Focus*
38
39 *Group).*
40
41

42
43 Many felt that they were unable to care for the person themselves, which is why they had had to
44
45 move into the care home in the first place:
46
47

48 *I dread to think what would happen [if she was not living in the care home], she*
49
50 *simply wouldn't survive. (Female speaker, Time 1, Focus Group).*
51

52
53 Participants appeared grateful that the homes provided 24-hour care, provided a safer environment
54
55 for the residents who were prone to falls or wandering, and knew that there was not really a viable
56
57
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1
2
3 alternative option. One participant spoke about how the care home was not without fault, but that it
4
5 was still a better option than being at home:
6
7

8 *Obviously it's a lot better that she's in care [than being at home], but you have*
9
10 *different problems. When she first went into care it was hard to put her there, but*
11
12 *we couldn't cope any longer. (Female Speaker, Time 2, Focus Group).*
13
14

15 **Gratitude**

16
17 Gratitude was a recurring theme during the focus groups, with many participants stating how
18
19 appreciative they were for the care that staff provided. Relatives also spoke about how grateful they
20
21 were that they had more time now that the care home had taken over all the tasks they had to
22
23 previously do:
24
25

26 *I do have more time. I don't have all her washing, I don't have all her ironing....it*
27
28 *has made it easier, and I can now go away and feel she's in good hands, whereas*
29
30 *before to go away was not easy. (Female speaker, Time 2, Telephone Interview).*
31
32
33

34 Having this extra time appeared important to several participants, particularly as many of them led
35
36 busy lives, juggling paid work, children, grandchildren and, in some cases, other relatives that they
37
38 also cared for.
39
40

41 *My mother in law's in care as well, and my dad is in his own home, but he's quite*
42
43 *demanding.....But I work as well. I have to be in the right frame of mind and I*
44
45 *have to have enough energy to complete that job of complaining. It's not easy.*
46
47
48

49 (Female speaker, Time 2, Focus Group).
50
51

52 Participants discussed feeling drained, emotionally and physically, and expressed gratitude that the
53
54 burden of care had been lifted, and their happiness that finally their relative was receiving the care
55
56 they themselves could no longer provide:
57
58
59
60

1
2
3 *In my case it's amazing...I have a life. I have spent an awful large part of my life*
4 *looking after people. And this is my moment. Now that I'm in my 70s, I've got*
5 *some freedom for the first time. (Female speaker, Time 2, Telephone Interview).*
6
7
8

9
10 The work of care staff was particularly appreciated by family members, who recognised that it was a
11 difficult, poorly paid job, that they could not do themselves:
12

13
14 *I'm very grateful for what they've done.... It's a job that I just couldn't do and*
15 *wouldn't do. (Female speaker, Time 1, Telephone Interview).*
16
17
18

19
20 This appreciation was felt across the focus groups. However, in some instances it seemed that this
21 led to family members making excuses for the staff when the care provided fell short. For example,
22 one participant's mother had not had her catheter bag attached properly, and it had slipped down
23 when they had been out in public. The daughter described this experience as 'undignified', also
24 saying that the staff member who had attached it needed to be taught how to do it properly, yet she
25 didn't raise the issue. Part of her reasoning for this was that she was really grateful for everything
26 that the staff did for her mother, so she would rather sort the problem herself than hurt their
27 feelings:
28
29
30
31
32
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36
37

38 *I'm just so grateful to them, I just don't want to hurt anybody's feelings, and it's*
39 *easy for me to hoick that up there before we go out. (Female speaker, Time 2,*
40 *Focus Group).*
41
42
43
44

45 **'Minimisation'**

46 Many focus group participants downplayed the issues that they had experienced. Comments
47 included 'it's not really that important', and that 'you're sort of finding something to complain
48 about, aren't you; it's not that really that important at the end of the day' (Male speaker, Time 2,
49 Focus Group). Participants discussed how they had to let smaller issues go:
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52
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1
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3 *But I find it so wears you absolutely down...I have to ignore some of it....there's a*
4 *lot of smaller things that I don't like, but it doesn't matter. (Female speaker, Time*
5 *2, Focus Group).*
6
7
8

9
10 Clothing repeatedly came up as an issue, particularly in instances where their relative had been
11 dressed in other people's clothing:

12
13
14
15 *They put mum as a size eight into a size 16 trousers.....and she walked and she*
16 *was trying to hold them up. (Female speaker, Time 1, Focus Group).*
17
18

19
20 One participant spoke about one occasion when his wife had been wrapped in a curtain instead of a
21 blanket, following a problem with the laundry. However, he said that he had not questioned staff
22 about this as he 'wouldn't make a fuss over nothing' (Male speaker, Time 2, Focus Group). Even
23 when discussing a resident who had been put in trousers that were 'six inches too short for her', the
24 reaction was that 'you can't expect perfection' (Male speaker, Time 2, Focus Group).
25
26
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30
31 Another person spoke about how she no longer minds if her mother is dressed in clothes that are
32 not hers, as long as the clothes fit:
33

34
35
36
37 *If it fits, and if they don't mind, I'm not that bothered...it's sweating the small*
38 *stuff really. (Female speaker, Time 2, Telephone Interview).*
39

40 41 **Guilt**

42
43 Guilt was a recurring theme throughout the focus groups. Many of the participants felt as though
44 they had let their relative down, and that they should be the ones caring for them. This was often
45 felt, despite knowing that they would not be able to provide the same level of care as the home:
46
47
48

49
50
51 *There's the guilt of having to send your mother into somebody else's care, and*
52 *even though the care is very good....there's the guilt that you could have coped.*
53
54
55
56 (Male speaker, Time 1, Focus Group).
57
58
59
60

1
2
3 Guilt was experienced, particularly when the participants had made promises to their relative not to
4
5 'put' them into a care home, which they subsequently broke:
6
7

8 *I found it very difficult to let go and felt very guilty, and always said I will never let*
9
10 *her go into one of those places.* (Female speaker, Time 2, Telephone Interview).
11

12 Several members also discussed the guilt they felt at being able to enjoy their own life, after passing
13
14 on the caring responsibilities to the care home.
15

16
17
18 *And I think if you are having a good time then there's the guilt that somehow it's*
19
20 *at the expense of having put someone, your mother, in the care home.* (Male
21
22 speaker, Time 2, Focus Group).
23
24

25 Another participant agreed with this, explaining how he is not able to feel 'happy' since his wife had
26
27 been in the care home:
28

29
30 *I'm doing much more, I get out...I couldn't get out before. But I don't do happy*
31
32 *any more. As long as this goes on I shan't. Even though you might go out and*
33
34 *enjoy that, you get back in the house and you're not happy. It doesn't take that*
35
36 *away, whether it's the guilt or whether it's just seeing them as they are.* (Male
37
38 speaker, Time 2, Focus Group).
39
40
41
42

43 Discussion

44
45 In line with previous research (i.e. Flynn Reuss *et al.*, 2005, Davies and Nolan, 2003), participants
46
47 from this study emphasised just how significant a life event it is to move a relative into a care home.
48
49 For some, the stress and anxiety associated with caring for a relative with long-term care needs was
50
51 still very much an ongoing process. Relatives discussed how grateful they were to the home for
52
53 relieving them of their caring responsibilities, whilst also expressing guilt (Davies and Nolan, 2003) at
54
55 no longer providing the care themselves at home. This guilt, coupled with their reliance on the home
56
57
58
59
60

1
2
3 to provide much-needed 24-hour care for their family member, appeared to inhibit them from
4
5 challenging the home when issues arose. Like Katz *et al.* (2013), we found that seemingly substantial
6
7 issues were sometimes downplayed, with one relative saying it was not worth 'sweating the small
8
9 stuff'.

10
11 Lopez *et al.* (2013) note that family members' foremost concern is often procuring basic care and
12
13 ensuring patient safety, rather than higher-level issues such as patient autonomy. Indeed, the Older
14
15 People's Commissioner for Wales (2014) found that families often have low expectations about
16
17 these higher-order aspects of quality of life in care homes. Such findings reflect Maslow's hierarchy
18
19 of needs (Maslow, 1943) and have been supported by previous research measuring social care-
20
21 related quality of life, which found that care homes in England tend to be very good at supporting
22
23 residents' basic needs but do less to meet their higher-order needs (such as control over daily life
24
25 and social participation) (Netten *et al.*, 2012; Towers *et al.*, 2016). Reasons for this are multi-
26
27 dimensional and might be partly attributed to traditional medical models of long-term care facilities
28
29 (i.e. Wild *et al.*, 2012), the culture within care homes for older people (i.e. Reed and Payton, 1997),
30
31 high levels of physical and cognitive frailty amongst residents (BGS, 2011), and inadequate staff-
32
33 resident ratios to support these higher-order needs (i.e. Kane, 2004).
34
35
36
37
38

39 In recent years there has been significant work to elicit culture change in care homes (such as that
40
41 undertaken by the 'My Home Life' programme) and address the need to 'work collaboratively with
42
43 people using services, their families and carers in the design and delivery of services' (Social Care
44
45 Institute for Excellence (SCIE), 2009). Davies and Nolan (2006) suggest that actively involving family
46
47 members has a positive effect both on the resident and the relative, with the latter maintaining their
48
49 own identity and sense of self-worth in the knowledge that they are making a positive difference for
50
51 their relative living in care. Policy has also emphasised the importance of personalisation through
52
53 person-centred and relationship-centred care and support (SCIE 2009). However, the findings
54
55 reported in this paper question the degree to which this is happening in practice. Much like previous
56
57
58
59
60

1
2
3 research (CQC, 2014; Davies and Nolan, 2006; Train *et al.*, 2005), we found that relatives were
4
5 concerned that their comments or complaints would be perceived negatively by staff. There was a
6
7 sense of exclusion from the care process and a reluctance to 'interfere' for fear of possible negative
8
9 repercussions for themselves and/or their relative. Rather than feeling like collaborators in the care
10
11 process, relatives seem to adopt a subordinate role (Michelle, 2007).
12

13
14 To be truly empowered to act as 'consumer champions', monitoring the quality of care being
15
16 received by their relatives (Sandberg, 2001), family members must feel that they have a voice and
17
18 could ultimately take their relative elsewhere. Although the policy rhetoric around personalisation
19
20 tends to focus on a notion of 'choice and control' in health and social care, in reality funding and
21
22 eligibility criteria for long-term care in England limit the choices for publicly-funded care home
23
24 residents from the outset. Self-funders too have very little opportunity to 'shop around', often
25
26 admitted by family members or care managers following a crisis, such as a fall or admission to
27
28 hospital (Forder and Allan, 2014). In neither case is it clear that residents, or indeed their families,
29
30 have time to consider several options and ultimately choose a home most suited to their needs
31
32 (Darton, 2012). As a relative in one of our focus groups put it, if there is a choice it is often a
33
34 'Hobson's choice' (Female speaker, Time 1, Focus Group).
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40 **Conclusion**

41 ***Implications of the study for practice***

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43 The Care Act (2014) highlights the important role of relatives and informal carers in maintaining a
44
45 service user's health and well-being once in care. Given that older care home residents are becoming
46
47 increasingly frail, with comorbid health conditions and often reduced cognitive capacity (BGS, 2011),
48
49 it is imperative that care homes create an environment in which relatives, friends and volunteers do
50
51 feel able to advocate on residents' behalf. However, this study highlighted that relatives felt
52
53 inhibited from challenging the home: an important finding care staff must acknowledge (even if they
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55 promote relationship-friendly practice) if they want relatives to act as the resident's advocate.
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3 Indeed, the similarity between the relatives' experiences in this study were striking, and together
4 suggest that more work needs to be done to convert political discourses into achievable reality.
5
6 Crucially, such sentiments are acknowledged by bodies such as the CQC, who are currently taking
7
8 steps to address these shortcomings, as discussed in the introduction (CQC, 2014). Until family
9
10 members are empowered to fulfil this role, relying on them as advocates will remain an inadequate
11
12 mechanism for driving high-quality personalised care. The following key points may help
13
14 practitioners achieve this:
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16

- 17
18 • Reducing relatives' feelings of guilt and building confidence in their 'right' to complain could
19
20 be addressed by giving them a say in the running of the home (through resident and family
21
22 groups/committees and joint working with staff), both during the initial phase of adaptation
23
24 to the care home and on an on-going basis.
25
26
- 27
28 • Foster an environment where issues and complaints are dealt with positively - thus
29
30 demonstrating the value of raising an issue.
31
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- 33
34 • Information-sharing of positive practice to address people's low expectations of care homes,
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36 for example promotion of 'Outstanding' CQC ratings, or of any involvement in research.
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39 There is therefore clearly still a need to implement more relationship-friendly policies, such as those
40
41 advocated by the 'My Home Life' programme. It is hoped that family members will then feel more
42
43 empowered to put into practice their belief that they should act as 'champions' for their family
44
45 members and, when required, question the home in an authoritative way, without fear of negative
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47 repercussions.
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49 50 51 **References** 52 53 54 55 56 57 58 59 60

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