

**"Thrown into the deep end": Mapping the experiences of young people living in a family affected by a neurological condition**

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Qualitative Health Research

'Thrown in to the deep end': mapping the experiences of young people living in a family affected by a neurological condition

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Abstract

In this case study research, we investigated the impact that having a parent with a neurological condition can have on young adults' experiences of growing up and the nature of their support networks. The work was informed by models of interface of chronic conditions and the family. Stroke (n=6), multiple sclerosis (n=14) and dementia (n=11) were selected as discrete cases. Within each case the researcher: 1. Carried out semi-structured interviews with young adults (16-25yr.) living in families affected by this condition and 2. Organized a workshop in which all participants reviewed preliminary themes and reflected on their support networks. A thematic analysis identified four themes: *The condition has shaped me; Thrown into the deep end; I need to talk about this; They don't understand.* A model of networks and support for these young adults was generated reflecting the need to increase their visibility and their access to support.

Background

At present, it is estimated that the number of people in England with a neurological condition (NC) has reached 12.5 million, with the prevalence of these conditions likely to increase as people live longer (The Neurological Alliance, 2017). People with long-term NCs have been found to have the lowest health-related quality of life of any long-term conditions (The Neurological Alliance, 2017). The UK Government is pushing towards a family-centred approach where the needs of everyone in these families are taken into account. Thus, addressing the needs of young adults in these families should therefore be a priority for service providers across the country. The number of young people who live in a family affected by a NC is expected to rise because of improved diagnosis and treatment, and as a result of couples waiting longer before starting a family (Gelman & Greer, 2011).

Transition from adolescence to young adulthood is the time in life where aspirations are followed, romantic relationships start and the need for independence develops. Research evidence has shown that a parental diagnosis of a NC at this time places significant stress upon these young people and this can lead to serious social and psychological consequences (Hall & Sikes, 2016; Pakenham & Cox, 2018). For example, recent studies have shown that parental stroke was strongly related to more behavioural problems in children particularly linked to internalizing and withdrawal behaviours (anxiety and depression) (Sieh, Dijkers, Visser-Meily & Meijer, 2012). Other studies looking at parental multiple sclerosis (MS) indicate that these children demonstrate more difficulties in how they relate to others and manage daily distress and show sustained emotional difficulties (Paliokosta et al. 2009). Finally, several studies have looked into the impact that dementia in the family can have on young people (Hall & Sikes, 2016; Hutchinson, Roberts, Kurrle & Daly 2016). For example, more and more families are taking on the care of a grandparent with dementia and this has been shown to impact on these children's everyday life and development into adulthood (Celdran, Villar & Triado, 2012).

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3 This study aimed to develop an understanding of the experiences of young adults living in
4 families affected by a NC and identify the nature of their support networks, including their
5 accessibility. It was informed by research evidence showing that the trajectory of NCs is often
6 unpredictable, involving symptoms ranging from physical disability through to psychological
7 impacts such as social withdrawal and mood changes (Pakenham & Bursnall, 2006; Hutchinson
8 et al. 2016). Hence, in order to minimize the impact of these symptoms on family life these
9 young adults take on a number of caring responsibilities as part of their daily routine, which
10 are likely to impact on their individual and social development. However, little is known about
11 how this caring role can affect young adults as they move into adulthood and have to balance
12 demands of their family with a natural drift towards becoming emotionally and economically
13 independent (Dearden & Becker, 2004; Allen, Oybode & Allen, 2009).

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29 It is difficult to estimate the number of young people in the UK who have a significant role in
30 caring for others. Carers are often 'hidden', partly due to a lack of awareness amongst many
31 professionals (Department of Education, 2017). According to workers in young carers' support
32 groups, these are often not tailored to address the particular needs of young adults caring for a
33 parent with a NC.

40 41 *Theoretical underpinnings*

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The theoretical framework for this study was the work of Rolland on chronic conditions and
their impact on families (Rolland, 1987; 1988). Informed by Rolland's (1988) model of
interface of chronic condition and the family (family/condition system), in the present study
the young adults were positioned as the central point with the family system interacting with
him/her and with the larger environment (extended support network, services and resources).
A theoretical proposition was that the impact of the NC may be affected by these interactions
as well as by support networks, resources and quality and availability of services. Rolland's

(1987) categorization of chronic conditions by psychosocial type was instrumental at the time of developing a tailored coding framework for data analysis. Furthermore, this typology informed the conceptualization and broad distinctions of onset, course and outcome and degree of incapacitation of MS, stroke and dementia as embedded ‘cases’ within the broader case of NC. Rolland’s modified ‘therapeutic quadrangle’ (1988) enabled an in-depth analysis of how a particular group of chronic conditions (NCs) interfaces with the health and social care team’s relationship with the family, the patient and the young adult independently.

Methods

Design of the study

This study followed a case study approach (Yin, 2008) to explore the overarching ‘case’ of NC and the experiences of young adults. This approach is appropriate in addressing ‘how’ and ‘why’ questions, providing in-depth understanding of phenomena and ‘real world’ context (Yin, 2008). In multiple case studies a range of ‘cases’ may be investigated to explore the research question and in this context three NCs were selected: MS, stroke and dementia as particular case studies. These conditions, although they have commonalities, are also linked to particular symptoms and trajectories and are inherently different in the way they develop and impact on a family’s well-being (The Neurological Alliance, 2017). The use of multiple case studies and triangulation are at the core of rigour in case study approach, combined with reflection and theoretical propositions underpinning the investigation to increase ‘credibility’ (Yin, 2008).

The study was conducted in North Wales (UK). Participants within each case study were young adults (16-25 yrs.) with a parent (or grandparent if in daily contact) with a NC (MS, stroke or dementia). These young adults were eligible to take part in the study regardless of the level of care that he/she provided. Participants were recruited mainly via social media platforms,

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3 advertising in sites of relevant organizations (e.g. young carers charities, MS Society, Stroke
4 Association, universities). All participants were provided with a participant information sheet
5 and asked to provide written consent. Parental consent is only necessary for children under the
6 age of 16. All participants in the study were 16 yrs. or older.
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13 Within each embedded case, the researcher carried out:

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16 Semi-structured interviews: semi-structured, face-to-face, audio-recorded interviews were
17 undertaken with study participants (for a copy of the interview schedule see Supplemental File
18 1). Interviews were carried out by Masterson-Algar who arranged to meet the participants at
19 their home or at the researcher's workplace at a day and time that was convenient for them.
20 Informed by Rolland's work (1988) the interview spine was specifically designed to capture
21 information about the impact of the condition from 'onset' to 'course' and 'outcomes', on the
22 young adult. Furthermore, it explored support networks and services including implementation
23 issues. Interviews were recorded and transcribed verbatim.
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35 Experience-based workshops: Participants from each case study were invited to attend. These
36 workshops followed the principles of experience-based co-production in which all participants
37 are involved as knowing subjects who bring their perspectives into the knowledge-production
38 process (Langley, Wolstenholme & Cooke, 2018). During the first part of the workshop,
39 participants had the opportunity to discuss and critique results from the analysis of interview
40 data (emerging themes) which the researcher presented. The second part focussed on exploring
41 support networks. Participants were asked to use a number of co-design tools including
42 modelling through mind maps, Lego, Play Dough or charts to display their thinking process
43 and represent their support networks at a given point in time (most relevant to them). In the
44 final part of the workshop, participants were provided with a copy of a modified version of
45 Rolland's (1988) therapeutic quadrangle. On this sheet, participants were asked to, individually
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3 make annotations (diagramming) reflecting their experiences of relationships and support
4 networks. The outputs were used to promote group discussion and have a final co-constructed
5 model. Workshops were audio recorded and transcribed verbatim. Finally, participants had
6
7 time to think about practical strategies to put the necessary support into action.
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13 Ethical approval for this study was obtained from Wales REC 5 Ethics Committee on the 6th
14 of October 2017 (REC 17/WA/0302). Written informed consent to take part in this study was
15 obtained from all participants in accordance with permissions.
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19 20 *Qualitative analysis*

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23 Transcribed data and hand-written field notes were converted into electronic text in order for
24 the researcher to create a 'case study summary'. As recommended by Yin (2008) each case
25 was viewed as a 'whole' before being considered across cases. Within each case, a thematic
26 analysis was carried out following the method described by Braun and Clarke (2006).
27 Masterson-Algar coded all transcripts from interviews and workshops. Crosschecking by
28 Williams was carried out with 30% of transcripts, to identify codes where there was lack of
29 clarity. When necessary, agreement on coding was reached through discussion. Overall, the
30 researcher then followed an iterative process of explanation building across cases. This analysis
31 involved revising findings from each case and comparing them against initial propositions
32 (Yin, 2008), reflecting the variety of data sources and potential insight that each of them could
33 offer in order to address study objectives.
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49 **Results**

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52 In total 14 young people were recruited into the MS case, 11 into the dementia case and six
53 into the stroke case. All participants were between 16 and 25 years of age, apart from three
54 who were 28, 29 and 30. 20 out of the 31 participants were female. In the MS case, nine
55 participants were female and five male and in the dementia case eight were female and three
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3 male. In the stroke case there was the same number of females than males. All participants had
4
5 a parent with the condition apart from four participants in the dementia case and two in the
6
7 stroke case whose grandparents were the ones with the condition. All participants reported
8
9 having daily contact and a close relationship with the family member with the condition. More
10
11 than half of the participants were engaged in education at different levels (e.g. secondary
12
13 school, college, undergraduate and postgraduate university degrees), two were in full time work
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15 and two had left paid work in order to become full-time carers to their parent. Within the
16
17 dementia and stroke cases most participants were teenagers at the time of their parent's
18
19 diagnosis. In contrast, nine of the participants in the MS case had been babies and young
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21 children at the time of diagnosis. None of the participants in the stroke case and only one in the
22
23 dementia case had been in regular contact and received support from young carers' charities.
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25 Six of the MS case participants had been part of their local young carers group from a young
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27 age.
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34 Two experience-based workshops, one for the MS case and one for the dementia case, took
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36 place. Seven participants attended the MS case workshop and eight participants the dementia
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38 case workshop. Due to unavailability (difficulties due to caring responsibilities or family
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40 circumstances) of the participants in the stroke case the workshop did not take place.
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43 **Themes identified across cases**

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46 Four themes were identified across cases (Table 1) which will now be described in detail:
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49 **Table 1** Identified themes and subthemes across case studies

51 Themes across all case studies	52 Subthemes
53 "The condition has shaped me 54 (and my family)"	<ul style="list-style-type: none"> 55 • Life decisions affected by condition 56 • Impact on social life outside family 57 • Conflicting feelings of need for freedom and guilt 58 • Condition as a motivator 59 • Impact on family life and relationships
60 "Thrown into the deep end"	<ul style="list-style-type: none"> • Learning as I go along – trial and error • Being terrified • Nothing can prepare you

	<ul style="list-style-type: none"> • Feeling abandoned • Friends 'give up' after a while
"I need to talk about this"	<ul style="list-style-type: none"> • I don't know how, it's very difficult • Only when I reach breaking point • Fear of being stigmatized and not being understood • But I don't want my family to worry about me • It is not easy asking for help • It has to be the right time
"They (people outside my family) do not understand"	<ul style="list-style-type: none"> • Awkward situations (when trying to explain) • My peers and teachers don't understand • Fighting preconceptions • If you haven't been through it you don't get it

Theme 1: The condition has shaped me (and my family)

During the interviews and workshops, young adults reported an awareness of how the condition of their close family member had shaped every aspect of their life. This, often generated conflicting feelings of need for freedom and independence with guilt linked to caring responsibilities. As two participants explained:

There was a sense of freedom that suddenly you're your own person. But also, this kind of guilt that you're away and someone else is now doing what you were doing. So, I think that was a struggle for a while. In first year, I considered quitting to go back home so that I could be with my family full time. (MS)

You're young and you still want that life and you're not able to because you can't go out to work and you feel you're already frustrated, and you feel that things aren't fair. (Dementia)

Young adults openly spoke about how the condition had impacted on their plans and changed the course of their lives. The parent's condition often had a negative impact on transitions into further education or the work market. As expressed by one participant:

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3 I knew the second he had it, “I’m not going to university in September.” Family
4
5 does come first in these situations, and as much as university is important, I had to
6
7 stay at home. (Stroke)
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9

10 In some of the cases, the condition had been a catalyst in itself, helping young adults develop
11
12 resilience and acting as a motivator. One participant explained:
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16 It made me, who I am today, and I wouldn’t be as motivated or as ... able to take
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18 everything that goes completely tits up and go... I’m fine with this. There have been
19
20 many times in my past when I had to just ‘step it up’ and carry on. I am the type of
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22 person who will keep going, as that stress is a motivating factor in life. Building a
23
24 hard exterior was the way to deal with it all. (MS)
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28 Family life was also reported to have been affected by the condition. For example, participants
29
30 often reported how since the condition, they had not been able to go on holiday. Overall, young
31
32 adults considered that the condition had shaped the relationships between family members.
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34 One participant explained how his relationship with his ill father had changed after his stroke:
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38 Before the stroke, I did definitely have a good relationship with my dad. Definitely,
39
40 that parent/child relationship, you know, fallouts. But nothing too major. After the
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42 stroke, still very good but through no fault of his own because of what he’s been
43
44 through, he can be quite temperamental. So he can lose his temper and stuff like
45
46 that. For the first couple of years, he was quite hard to be around. He didn’t feel like
47
48 my dad, if that makes sense. Felt like a completely different person. (Stroke)
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52 The same participant explained how his relationship with the rest of his family (siblings) had
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54 also been impacted:
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57 Sadly, during that time, you’d think it would really bring a family together, which
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59 it did in some ways, but in other ways, brings you apart a little bit because you stop
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3 spending time with each other. There's so much that you miss in each other's lives
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5 because you just haven't got the time to catch up on that. (Stroke)
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8 **Theme 2: Thrown into the deep end**

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11 Young adults reported finding out their own particular ways of dealing with the condition. One
12
13 of the participants for example, explained: "*I find it valuable to try and see the world as she*
14
15 *does, imagine what it must be like*" (Dementia). However, young adults admitted that once
16
17 their family member was diagnosed, nothing could have prepared them for what lay ahead and
18
19 they unanimously reported feeling or having felt 'abandoned' after diagnosis. As a participant
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21 clearly explained:
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26 After the consultation ended, we got given a bunch of leaflets and phone numbers,
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28 which were no use to us at the time. Even to today, they still aren't relevant. You
29
30 get a name of what is wrong but no instructions on how to cope. (Dementia)
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34 Young adults reported mixed feelings and approaches to dealing with the diagnosis, which was
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36 often described as the 'unknown'. Fear and anxiety were triggered around the time of diagnosis
37
38 and often remained common feelings affecting young adults. A participant explained how her,
39
40 and her family were 'terrified':
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44 We were going through everything (diagnosis), no support for us during this time,
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46 so we were in limbo, really, not knowing. Mum's a very strong person so she was
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48 keeping a strong face and saying that it's fine, everything's ok. But obviously we
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50 were all terrified. (Dementia)
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54 Another participant who is a carer for his mum with younger onset dementia explained:
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57 Not so much thrown in, more like wading into a cold ocean, you have this idea of
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59 how it's going to be and there is a lot of fear 'it's going to be so cold' but when you
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3 dive in it's completely different to how you expected and it's a relief to let go of
4 those old issues. The deep end is a mystery, a complete unknown, there is
5 uncertainty and if I refrain from trying to make sense of it, trying to predict, I can
6 enjoy the mystery, swim deeper into the unknown. (Dementia)
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13 Young adults often described the support as primarily focussed on the person with the condition
14 and reflected on the impact that this had on the rest of family members. Young adults described
15 feeling neglected as a consequence of the strong focus of services on the ill parent. One
16 participant explained:
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23 It was all about my dad's recovery, which of course was very important and at the
24 time that was all we cared about. But, in hindsight, sometimes you realise, if we
25 had looked after ourselves a bit more back then, would we all be in a bit more of a
26 better place now? But no, we never received anything, any leaflets, any phone calls,
27 anything. It was all related to groups for my dad, for my dad to meet new people,
28 my dad to socialise, but never, never for the family. (Stroke)
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37 In regard to the role of schools, young adults overwhelmingly reported a lack of support and
38 how during their time in secondary school or college they had never been taught or discussed
39 issues related to NCs. Similarly, young adults described feeling let down by friends as time
40 passed and the condition progressed. Often, friends' support was reported as being inconsistent
41 and not reliable:
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49 I think people, at first -. You know, we all got calls saying, "I'm so sorry!" But I
50 think people almost are scared to get involved in it because they think, "This is a
51 bit beyond my comprehension. I don't want to get involved. A lot of them
52 eventually drop off the radar, because if you don't stay in touch with them if you've
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3 got so much going on in your life, I think eventually they think, “Oh. I give up”.

4
5 (Stroke)

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8 Young adults often talked about the difficulties of learning how to deal with the condition
9 through ‘trial and error’ and having feelings of not knowing whether they were doing things
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13 ‘right’. As two participants reflected:

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16 It’s great to learn something through trial and error to benefit other people in the
17
18 future, but when the trial and error is about your own father, then it’s like really, I
19
20 don’t want to be the one making mistakes. I want someone to be here. (Dementia)

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23 At first, it was a lot of shouting and things like that which was because we did get
24
25 thrown into the deep end. It was, that’s how I was gonna cope. I’m gonna shout at
26
27 everybody and I was taking it out on people that weren’t doing nothing. (Dementia)

28 29 30 31 **Theme 3: I need to talk about this**

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34 Young people overwhelmingly reported how they often feel the need to talk about the things
35
36 they are going through. Talking to others was often described as a way to make sense of the
37
38 situation and release feelings of frustration and unfairness. As two participants explained:

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41 “Please eat this meal!” It was for about eight days where she only ate trifle because
42
43 she wouldn’t open her mouth to anything else. But very frustrating and you feel,
44
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46 “Who can I talk to about this? (Dementia)

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49 I find tremendous benefit even just by being able to go over there and take a break
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51 or talking it out and allowing those emotions to arise and sometimes I think once or
52
53 twice I’ve been with a friend and I’ve just burst our crying. (Dementia)

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3 However, speaking about their family member and their condition was described as very
4 challenging and requiring high levels of confidence and mental strength. As a result, young
5 adults explained that often important issues were not addressed and remained unspoken.
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10 Participants also explained how being able to talk to someone going through similar issues
11 whilst in secondary school would have been extremely beneficial in order to help normalise
12 their situation and reduce feelings of 'being the only one'. As put by one participant:
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18 If when I was in school, especially around sixth form, if someone came up to me,
19 I'd jump at the chance because it's almost like being the only person that you know
20 of with someone in your family who has MS. (MS)
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26 Self-help was often described as young people's default approach and that only the situation
27 reaching crisis point would motivate them to speak out and seek support from friends. In their
28 words, avoiding disclosing information was in balance, easier than accepting the need for help.
29 One participant reflected, "*I don't tell my friends until I reach breaking-point, then I might say*
30 *something, but I just rely on myself*" (MS).
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38 Feelings of shame and fear of being stigmatized by peers and teachers was often reported as a
39 major barrier to talking about their situation and their family member's condition. Young adults
40 overall considered that by disclosing information they would be at risk of being singled out.
41 Remaining silent on the other hand was reported as having had a negative impact on the
42 development of these young adults' personalities and their mental health. As one participant
43 put it:
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52 Being a young carer felt like a substantial element of my identity when growing up
53 but felt as though it was a secret. In turn, I felt that I was hiding a large proportion
54 of my character on the basis that people would not understand. By the time I was
55 less ashamed to tell people about it, I felt that it was too late to get any real help for
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3 it. It had already moulded my character and was ingrained into my mental health.

4
5 (MS)

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8 Young adults, in some cases, explained how they had chose to remain silent to avoid further
9 complications within the family. In a participant's words:

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13 I also tried to hide it because it's my dad's mum and he's upset and I didn't want to
14 cause more problems by saying, "I have problems" (Dementia)

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19 Feeling emotional and wanting to avoid showing signs of defeat or weakness were two other
20 reasons behind young adults remaining quiet. Young adults overwhelmingly stated that for the
21 uptake of support services to increase, the help provided should be actively offered without
22 expecting those in need to ask for it. One of the participants whose mum has MS explained
23 how during his time in secondary school he was not able to actively seek the help:

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28 I think it was just a particularly tough week and my head of sixth form called me in
29 like, "Is everything ok?" And I was just like, "Not really." And then she was like,
30 "There are things out there." And I was like, "No, I just want to do my study and
31 carry on and pretend as if it's normal." And then a month later, I was like, I kinda
32 wish I had the opportunity to be offered that again but I don't want to ask for it. I
33 think, because asking for it is almost like admitting defeat. Whereas, if someone is
34 giving it to you on a plate, you're like, "Ok, yeah." (MS)

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39 Time was reported as an important variable. Young adults reflected on how they needed time
40 to 'get ready' to talk about their family member's condition. As a participant reflected:

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53 So, whilst, in the moment of diagnosis you're like, "I need all this technical
54 specification. I need to know about that." Six months after you've processed, and
55 you've gone through a lot and you just want someone who's kind of similar to you
56 and has had similar experience. (Dementia)

Theme 4: They (people outside my family) do not understand

Across all three case studies, young adults overwhelmingly reported a lack of understanding of peers and teachers about the NC and its impact. As a result, speaking out often led to young adults having to spend time clarifying and defining the condition, which was frequently described as a source of stress. As put by one participant:

” What does your dad do?” I just say, “He’s disabled, he doesn’t work.” It’s crazy, I think some people feel quite uncomfortable. They don’t know what to say. Obviously, they say, “Oh, I’m sorry.” But nothing other than that. (Stroke)

Young adults considered that it was difficult to avoid and to deal with people’s preconceptions about the condition. In the case of MS, one participant explained:

The amount of times I’ve gone down the street with mum and someone has said to her, “You’ve got MS? Nah!” They are simply thinking of it, like, “Oh, she hasn’t got crutches. She hasn’t got a wheelchair or a mobility scooter so she can’t have it” (MS)

Also, young adults were clear in considering that it is only through personal experience that people could understand the impact of the condition. According to one participant: “*They haven’t been through it and they don’t get it*” (MS). A young woman whose dad has younger onset dementia reflected:

No one knows what it’s like unless they have been through the same experience. Especially when you are young and have all this ‘extra’ responsibility. My friends don’t understand how much I personally have to do at home. It’s hard to enjoy yourself sometimes; it’s always at the back of your mind. People wonder what is wrong and you feel like you can’t explain because it’s so much more than just ‘a bad day’. (Dementia)

Within-case themes

Two themes were identified as case-specific. These two themes did not support emerging themes across all three cases. However, they provide an account of the reflections of most of those participants in the dementia case study. The inclusion of these two themes confirms patterns emerging from data analysis that should not be excluded.

Grief – it is like ‘dying twice’

All young adults in the dementia case study reflected in detail about dealing with grief at different stages of the condition. During the interviews and in the workshop, young adults discussed how they had learned how to cope with losing their family member, as they knew them, somewhere along the line. One participant reflected:

The loss of my dad’s personality, his essence is gone but also the loss of that particular family dynamic and the relationship we had. Completely unconnected to his physical presence. There’s no emotional connection there. Last time I tried to hug him was about two years ago. It would have been this time two years ago. I went for a hug because I’d just come back from somewhere for three days and I hadn’t seen him and I went to hug him and my mum was in the room and I put my arms around him and his arms were to his side and he kind of recoiled like it was this very unnatural thing to do. (Dementia)

I can’t do this anymore

Young people in the dementia case study reported on the difficulties linked to the transition from caring at home to institutional care. Reaching a breaking point was often the trigger to making the final decision. Young adults reported conflicting feelings of relief and guilt:

1
2
3 Yeah, even though I was very clear that I couldn't do it any longer, it was very
4 difficult to let someone else do it. You felt guilty, really, and that we were letting
5 her down. I remember Mum would always say, "Don't you dare put me in a
6 home," you know when we were kids? And we were like, "Oh, no, we won't."
7 But you know, she's happier there, now. When she was at home, she was
8 constantly asking to go home and was scared. Not once has she asked to go home
9 since she's been there. (Dementia)

10
11
12 Young adults also reported how they had played an important role in this transition, often being
13 the ones having to confront family members in order to make the final decision. As one
14 participant put it:

15
16
17 It was when my dad was that confused and seemed to be having hallucinations
18 that he started to turn aggressive. It got to a point where I had to step in-between
19 him and my mum. It was at that point where we could tell that he was wanting
20 to hit out and I had to literally get in front and stop that from happening. It was
21 at that point. Me and my sister said, "Right, care home is the answer. We don't
22 care, mum. You're in jeopardy." (Dementia)

23 24 25 **Modelling relationships and support networks**

26
27
28 As part of the modelling facilitated by the workshops, young adults in the dementia and MS
29 cases constructed symbolic representations of their support networks. This activity illuminated
30 the complexity and distinct nature of support networks linked to each condition. It was striking
31 that although there were distinct characteristics at an individual and condition-specific level
32 there was also common themes that bound them. Two exemplars are selected to illustrate these.
33
34 Figure 1 shows the support network model created by one of the participants in the MS case.

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INSERT FIGURE 1

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3 As explained in his words:
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6 When my dad was diagnosed, she really took it upon herself to shelter me from
7
8 it as much as possible. My mum is there at the front. I'm the king, there, at the
9
10 back on the elephant. The elephant is a distraction. 'The elephant in the room'.
11
12
13 You don't talk about it.
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15

16 This model is an example of how support networks for these young adults are often very small
17
18 and heavily reliant on the 'healthy parent' who takes up a protective role. Figure 2 is a
19
20 representation of a very different support network created by a participant in the dementia case.
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23 As described by the participant:
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26 The ball represents my sanity/wellbeing sort of thing. So, there's three main
27
28 support networks I have and then there is barriers around each one. The first
29
30 support network I'd go to would be my knowledge (cog pieces). So, I'd research
31
32 about things, because I've always loved science and stuff, so that's my main one.
33
34 My second would be Facebook (animal pieces). So, there's this page for people
35
36 going through the same thing, and that's really helped a lot. It reinforces the fact
37
38 that you're not alone and other people are experiencing the same. Then my
39
40 friends and family etc. (human figures), they're the last resort. They're the last
41
42 resort but you don't want to tell your friends everything because you want a
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44 separate life to the dementia life. So, my friends, if both of these fail then I always
45
46 have my friends as a safety net.
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52 INSERT FIGURE 2
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55 In this model the role of family and friends is considered a last resort or a 'safety net' that is
56
57 present when all other support systems fail. Young adults in all case studies expressed
58
59 conflicting and varied opinions regarding the supportive role that online tools (e.g. blogs,
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1
2
3 Facebook) played in their everyday life. Whilst some participants considered them a real source
4
5 of support (Figure 2) for dealing with feelings of loneliness, for others these tools were not part
6
7 of their support networks and were often perceived with suspicion and mistrust.
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10
11 Overall, the modelling exercise revealed that participants' experiences of living in a family
12
13 affected by a NC, were closely linked and affected by the strength and presence of support
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15 networks. The work of Rolland (1988) provided a catalyst for 'fleshing out' further the thematic
16
17 areas uncovered during interviews with young people and the analysis of the modelled
18
19 representations of networks.
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22
23 The final part of the workshop where participants were able to make annotations on the
24
25 modified version of Rolland's (1988) therapeutic quadrangle generated a series of iterative
26
27 accounts. Participants heavily annotated the model using arrows of different widths (denoting
28
29 strength of network and support as well as direction and inter-connection), colours (using a
30
31 'traffic light' system) and written comments. In Figure 3 two examples from the dataset are
32
33 illustrated. These highlighted the dynamic and complex range of interrelationships between the
34
35 stakeholders (family members, parent with the condition and services) and the NC. The
36
37 individual account shown in Figure 3A (dementia) is a model of support networks heavily
38
39 reliant on all family members (represented as thick green arrows). On the other hand, Figure
40
41 3B (MS) shows an example of a network heavily centred around a strong relationship between
42
43 the young adult and the ill parent (represented as thick green arrow) and little support from
44
45 other close family members (siblings). Both examples illustrate firstly, a lack of family centred
46
47 approaches and a lack of tailored support for the young adults from the NHS, social services
48
49 or the third sector (both represented as a thin red arrow). Secondly, a tendency of formal support
50
51 services to become available only at a time of crisis (represented as amber thin arrows).
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58 INSERT FIGURE 3
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Synthesis: A therapeutic quadrangle of networks and support for young adults

An iterative process of analysis and synthesis reflecting the variety and potential insight of all data collected during interviews and workshops resulted in an overarching co-constructed model that captured the experiences of young people as part of the across case analysis. This modified *therapeutic quadrangle of networks and support for young adults* was informed by all data sources collected in this study (Figure 4).

INSERT FIGURE 4

Within this model the two-way relationships between four constructs (young adult, close family members, parent with condition and formal support) are well established and unavoidable (represented as black arrows) and the NC takes centre stage. The dynamic nature of how support networks are experienced is again represented using a ‘traffic light’ system and arrows of different widths.

The upper half of the quadrangle represents family-based support networks. Young adults relied strongly on the ‘healthy parent’, as did the parent with the condition. One participant explained: “*I think she is the rock of the family. I wouldn’t do it without her. She’s wonder woman. I don’t know how she does it*” (MS). Other close family members, often siblings, were considered a source of support. As one participant put it:

So, we always go back to my mum [healthy parent]. And then if my mum’s not there my sister will come to me because I feel she thinks I’m the next person down. Which I like. She’s the older one [Laughs]. (Dementia)

Young adults also reported finding support in siblings at the time of sharing the caring responsibilities and ‘fit them in’ around their lives:

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2
3 It sort of fell on me and my little sister to take the reins a little bit. But we've
4
5 come up with a fair system, where, for example, while I'm at uni they do a little
6
7 bit more and then when I come home, I do a little bit more. We try and distribute
8
9 it as much as we can. (Stroke)
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11
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13 These support networks were seen as 'working' and are were therefore denoted as green in
14
15 colour and strong (represented as a thick line). The support links between young adults and
16
17 their ill parent were also strong and 'positive'.
18
19

20 The lower half of the therapeutic quadrangle model represents a number of areas of concern.
21
22 As evidenced in Theme 2, young adults reported a lack of family-centred support from services
23
24 (NHS, Social Services, and third sector organisations). Also, there was an absence of support
25
26 from these services that targeted young adults specifically (represented as red lines). Finally,
27
28 the model illustrates the support that the parent with the condition receives from formal services
29
30 (e.g. NHS) with an amber line reflecting that although there is support available, it is often
31
32 inconsistent, unreliable and only triggered as a result of the condition reaching crisis point.
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36 37 **Discussion** 38 39

40 The outcome of this study is a theoretical model that identifies a range of interacting factors
41
42 that play a role in defining the support relationships of young adults living in a family affected
43
44 by a NC. Furthermore, the results here presented offer qualitative evidence of the serious and
45
46 lasting impact that NCs can have on the lives of these young people living. Our results are in
47
48 line with studies reporting that these conditions can often have adverse impacts on children's
49
50 emotional wellbeing and resilience (Pakenham & Bursnall, 2006; Boström & Nilsagård, 2016;
51
52 Hutchinson et al. 2016). In this article we report how young adults' family members' condition
53
54 has had a strong impact in their ability to open up to teachers and peers, socialize and grow up.
55
56 Sieh et al. (2012) described a similar relationship between parental stroke and children's
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1
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3 withdrawal behaviours. Our results show that not only these conditions have negative
4
5 consequences but also that often, these are never resolved since the wellbeing and health of the
6
7 ill parent comes first to the needs of family members. Hence, this study adds to the body of
8
9 knowledge advocating the need for formal support systems and health care professionals to pay
10
11 attention to these young people (Boström & Nilsagård, 2016). This would benefit both, the
12
13 young adults and their parents, who worry about them.
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16
17 Our study participants also reported positive aspects of having a parent with a NC. Some
18
19 described their parent's condition as a motivational factor that had made them focus on doing
20
21 well in school and had also helped them become more resilient. The study by Gelman and
22
23 Greer (2011) on young children in younger onset dementia families and Razaz, Nourian,
24
25 Marrie, Boyce and Tremett (2014) review on the impact of a parental diagnosis of MS reported
26
27 very similar findings.
28
29

30
31 Theoretical models have been successfully used to represent complex social interactions and
32
33 support pathways of different groups such as for example, people who have experienced
34
35 childhood trauma (Stige, Træen & Rosenvinge 2013) or women living in isolation (Harvey
36
37 2014). The model of therapeutic quadrangle of networks and support for young adults
38
39 presented here provides an overarching account of how these young adults perceive and
40
41 experience current support services. It also highlights areas where support is most lacking.
42
43 Young adults in our study confirmed what other evidence has already suggested. Firstly, that
44
45 the way support services are currently organized is not family centred but patient centred
46
47 (Boström & Nilsagård, 2016). As a result, 'healthy' members of the family are left behind and,
48
49 as our study shows, this can have a perceived negative impact on their wellbeing and
50
51 development. Secondly, that support from charities such as those targeting young carers,
52
53 although described as very relevant, is often inconsistent, with some young adults not aware of
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55 this type of support during their teenage years. Reported feelings of isolation and withdrawal
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3 can, in turn be a significant factor impacting on the ability of services to reach out to those
4
5 young adults in need. As reported here, identifying those that need the support is complex and
6
7 relies strongly on schools and organizations increasing their knowledge on the subject and
8
9 learning how to break down/minimize barriers (Gillespie & Campbell, 2011). Young adults
10
11 also reported a need for more support initiatives in schools. The difficulty that these young
12
13 adults face at the time of seeking help and talking about their challenges with peers and teachers
14
15 emerged as a complex and multidimensional phenomenon. Preconceptions regarding NCs
16
17 often played a major role in these young people's decision to remain silent and avoid disclosing
18
19 their family member's condition to peers.
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23
24 These results corroborate earlier findings on the impact of preconceptions and the risk of
25
26 stigmatization (Werner, Goldstein & Buchbinder, 2010; Hutchinson et al. 2016). This study
27
28 has provided evidence to suggest that currently there is very little awareness around NCs
29
30 amongst secondary school, college and university staff and peers and that this leads to these
31
32 young adults keeping quiet due to the worry of being treated differently or stigmatized. In turn
33
34 students often become socially excluded and isolated, and as a result fail to reach their academic
35
36 potential (Bolas, Van Wersch & Flynn, 2007; Richardson, Jinks & Roberts, 2009; Nagl-Cupal,
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38 Daniel, Koller & Mayer, 2014; Mackenzie & Williams, 2018). The UK Government is
39
40 currently pushing strongly for health and education services to work together in order to
41
42 improve the wellbeing outcomes for children and young people (Department of Education,
43
44 2016). Schools have a responsibility and at the same time are the ideal environment to support
45
46 young people (Paliokosta et al. 2009; Chikhradze, Knecht & Metzger, 2017). Hence, some
47
48 secondary schools have initiatives in place to address young carers' needs (e.g. drop in sessions
49
50 organized by young carers charities). However, our findings join the evidence suggesting that,
51
52 at present, schools are not providing opportunities to openly discuss the impact that living in a
53
54 family affected by a health condition can have on a young person's everyday life (Reupert &
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3 Maybery, 2009; Boström & Nilsagård, 2016). Also, as previously discussed, these initiatives
4 heavily rely on young people actively seeking help. Our theoretical model of young adults'
5 support networks reflects this and shows that, ultimately, young adults living in a family
6 affected by a NC will tend to 'self-help' and strongly rely on a close family member (often the
7 'healthy parent' or a sibling) for unconditional support.
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10 11 12 13 14 15 *Limitations of the study*

16
17
18 The study was able to recruit young adults for all three case studies. The majority (20 out of
19 31) of participants were female. It could be possible that female young adults are more likely
20 to become the carers for their ill parent. However, further work will be required to test this
21 assumption. Although recruitment was successful, it was very challenging to recruit
22 participants in families affected by stroke who were available to take part in the interview and
23 attend the workshop. Hence, it was not possible to carry out an experience-based workshop
24 within this case. A number of young adults were invited to take part in the study but declined.
25 The sudden trauma that stroke brings upon families could be a reason that explains the
26 difficulty in reaching out to these young adults. When the trauma is very recent and the family
27 is in the process of adapting young adults are very unlikely to be able to join. Similarly, once
28 the adaptation period is over young adults are likely to "*want to get on with their lives*", as
29 some young adults in this study voiced. Our study included six young adults living in families
30 affected by stroke. Although we acknowledge the fact that our small sample does not allow for
31 generalizable results that could be transferred to other cohorts, we are confident that this study
32 provides detail experiential information about the lived experiences and support networks of
33 these young people.
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54 55 56 **Conclusion**

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3 Our study has firstly explored the subjective experiences of young adults living in a family
4 affected by a NC and secondly, provided further evidence on the perceived impact that this can
5 have on their wellbeing and development as they approach adulthood. Finally, we present a
6 model that can facilitate the understanding of the complex dynamic nature of the support
7 networks and relationships of these young adults and their families. Our results show that the
8 impact of these conditions is complex and multidimensional. Young adults reported feelings
9 of abandonment and lack of support from school, peers and services throughout the duration
10 of the condition. Lack of understanding of NC and their impact was perceived as a barrier to
11 accessing very much needed help due to people's preconceptions and fear of being stigmatized.
12 More initiatives need to be put in place to identify and support these young people. We suggest
13 the need for more research on this topic. Studies based in secondary schools exploring
14 interventions that generate meaningful conversations around these conditions and their impact
15 on everyday life can help bridge the silence and identify those in need.
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35 their vital contribution
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58 **Figure legends**

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3 **Figure 1.** Example of a support network created by one of the participants in the MS case.
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6 **Figure 2.** Example of a support network created by one of the participants in the dementia case.
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9 **Figure 3.** Two examples of individual annotations on a modified version of the therapeutic
10 quadrangle model (Rolland, 1988) reflecting support networks and relationships. A: Example
11 by a participant in the dementia case and B: Example by a participant in the MS case.
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16 **Figure 4.** Therapeutic quadrangle of networks and support for young adults living in families
17 affected by a NC (based on a modified version of the therapeutic quadrangle model by Rolland,
18 1988).
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For Peer Review

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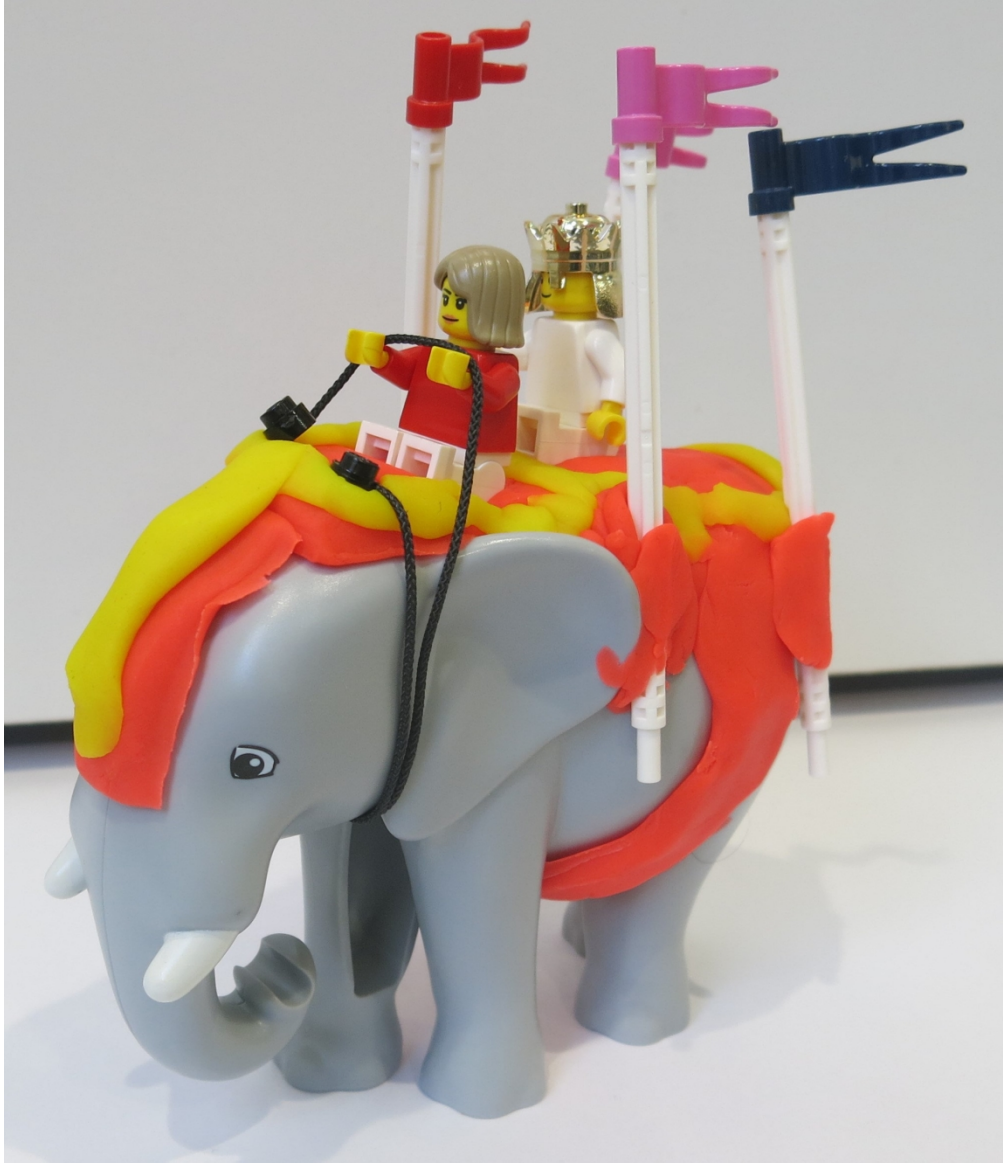


Figure 1. Example of a support network created by one of the participants in the MS case.

64x74mm (800 x 800 DPI)

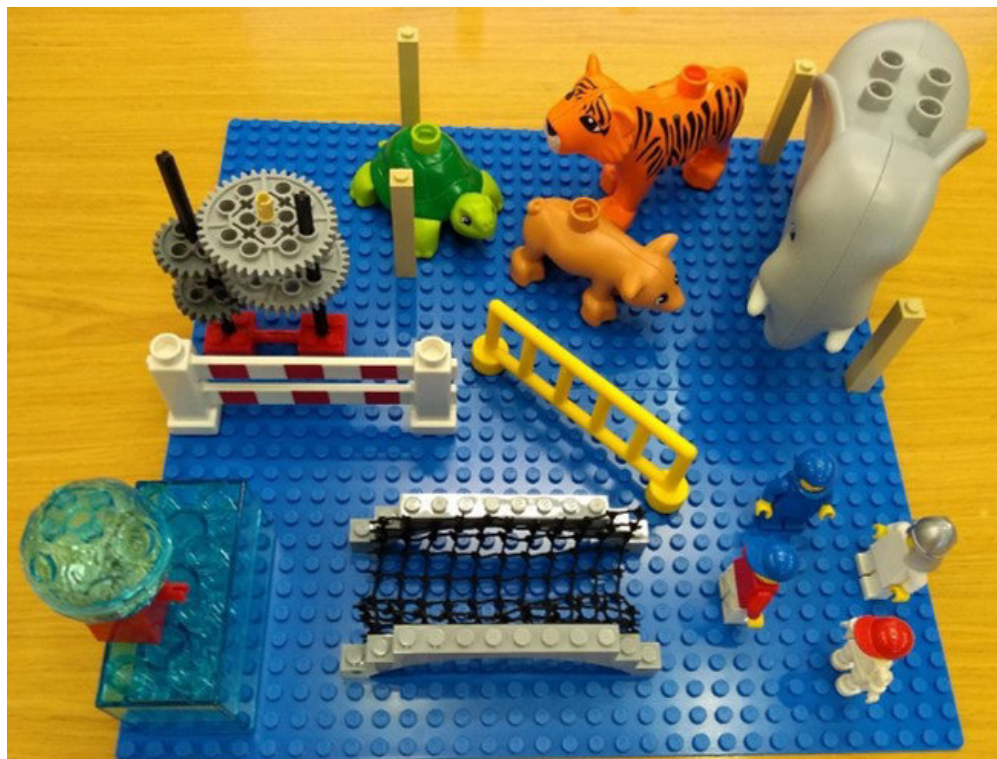
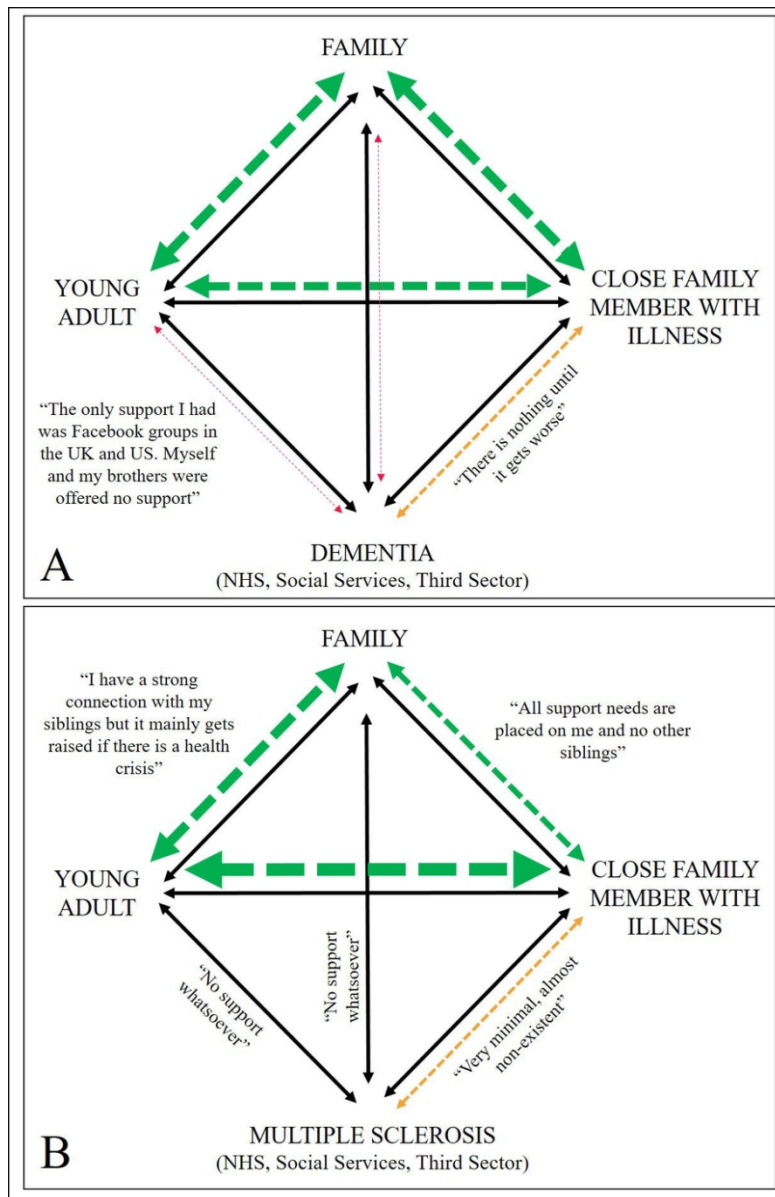


Figure 2. Example of a support network created by one of the participants in the dementia case.

20x15mm (800 x 800 DPI)



45 Figure 3. Two examples of individual annotations on a modified version of the therapeutic quadrangle model
46 (Rolland, 1988) reflecting support networks and relationships. A: Example by a participant in the dementia
47 case and B: Example by a participant in the MS case.

48 39x60mm (600 x 600 DPI)

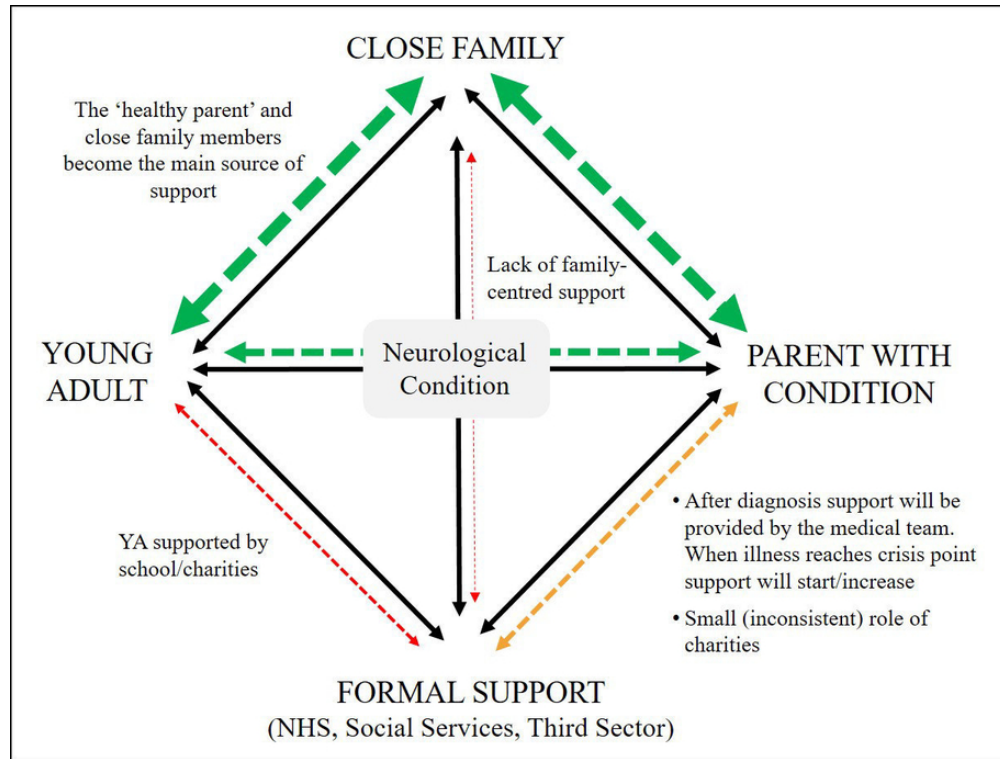


Figure 4. Therapeutic quadrangle of networks and support for young adults living in families affected by a NC (based on a modified version of the therapeutic quadrangle model by Rolland, 1988).

38x29mm (600 x 600 DPI)

PREAMBLE

Many thanks for taking the time to help with this interview.

This interview is being carried out to gather information about the experiences and opinions of young adults living in a family affected by a neurological condition. I would like to find out how you feel about the support you have received (if any). If at any time you want to stop, or have a break or you don't want to answer a question please let me know. Please be assured that all what you say will remain confidential but may be anonymously quoted.

Can I ask you to confirm that you are happy to continue, and for the conversation to be recorded. If you are not I can make notes instead.

Icebreaker: Please can you tell me a little bit about you and your family

Can you tell me a little bit about how your parent's diagnosis and how it affected your everyday life?

- Were you able to continue doing the same things you did before? What made that possible? Who took on the main caring role?
- Do you remember if anybody explained properly what was happening? Whom did you go for information?
- What did you struggle with the most during those initial moments? And after?
- Was your school/university supportive? In what way? Did you talk to your teachers? What did they do to support you?
- Has your life changed since your parent's diagnosis? In what way?

Can you tell a little bit about the support that you have received since your parent's diagnosis?

- Where (to who) do you go for support?
- Who do you talk to about your parent's illness and your worries?
- Have you ever been asked 'what do you need'?
- Who organized it? Did you look for it or was it offered to you?
- Do you remember any particular person/service that was quite useful (or the opposite)?
- Would you say there was a family oriented approach?
- When was the time that you most needed support?

Do you know what the term 'peer support' refers to?

- Have you heard of this term?
- What does it mean to you?
- Do you find that talking to others in a similar situation to you is helpful? Have you ever met anyone in a similar situation to you? What did you get out of the experience?

1
2
3 **Have you ever attended or been involved in any form of peer support?**
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- 5
- 6 • If yes, how did you find out about it? Was it easy or difficult to find? Did you know where to
7 ask for it? Was it offered to you without you asking?
 - 8 • Did you feel it was tailored to your needs? For example, did it address the challenges that
9 you face because of your age (time for important decisions)
- 10

11 **Do you think peer support can be a useful way to cope with challenges?**
12

- 13
- 14 • Do you think it is particularly good for young people? Why?
 - 15 • Do you think it suits everybody? Why? (Do you speak easily with your family? Are you the
16 type of person that is happy sharing things with family and friends?)
 - 17 • What do you think about 'passing on' what you have learned from your experience to
18 others?
- 19

20 **What do you think about online sources of support (e.g. blogs, social media etc.)?**
21

- 22
- 23 • Do you use Facebook or Twitter in order to voice concerns or find out about things?
 - 24 • Do you use any of them? Why?
 - 25 • Can they help? Why?
- 26
27

28 **To end:** *I have asked you all the questions I wanted to ask you, is there anything you would*
29 *like to say or any other issue I haven't mentioned that you would like to discuss?*
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31 **Thank you very much for your help.**
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