

Doing Better in Health Care



Supporting Family Carers of
People with Learning Disabilities



FUNDED BY



Manchester
Metropolitan
University

Sibs
For brothers and sisters
of disabled children and adults



NIHR | National Institute for
Health and Care Research

Introduction

The Spinning Plates project set out to explore the mental health experiences of family carers of adults with learning disabilities.

We did this by:

- Reviewing existing research about the mental health of this group of family carers.
- Interviewing family carers.
- Supporting people to create short films about their experiences.
- Curating an online exhibition of contributions.

This resource is based upon the research findings.



Learning Outcomes

- To better understand the experiences of family carers of adults with learning disabilities.
- To integrate this understanding into the support General Practitioners (GP) and GP practice teams provide to family carers of adults with learning disabilities.

Terminology

We use the term 'family carer' to refer to friends and family members, birth families and adopted family members, including parents, partners and siblings of people with learning disabilities who provide unpaid care on a regular basis to a person with a learning disability. The terms 'unpaid carer' and 'informal carer' are sometimes used alongside 'family carer'. We use the term 'family carer' as the term preferred by the carers we worked with [1].



Discussion point:

Do you ask carers of adults with learning disabilities how they would like you to refer to them?

A note about the resource content

We hope you find this resource useful and informative.

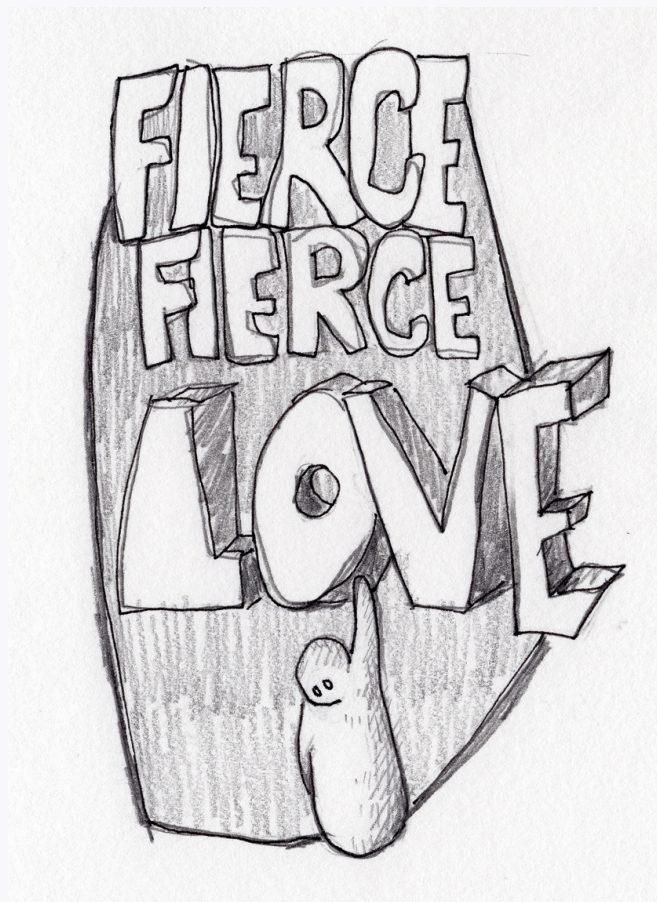
Please be aware that whilst love and joy are present throughout the resource, there is anger, sadness and distress present too. There are also illustrations throughout the resource that some people might find emotive.

PART 1

The Love

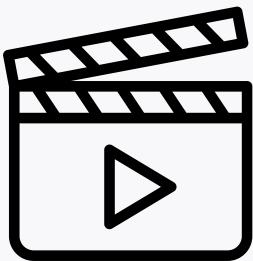
Love drives family carers' care, advocacy and activism. This love can be exploited by health and social care systems. Family carers are denied basic information, support, and kindness.

Many family carers experience mental health difficulties. They reject the idea that caring for a person with a learning disability is always a threat to their mental health.



Family carers have different experiences and understandings about the causes of their mental health difficulties and these change over time. However, many carers believe their mental distress is caused by the constant fight for services and support. Many family carers have struggled for the right support for the person they care for over decades.

It is important to understand care continues to be a deeply gendered practice. Mothers and sisters take on the vast majority of care.



Sophie's film explores love in the context of sibling care. You can watch the film here

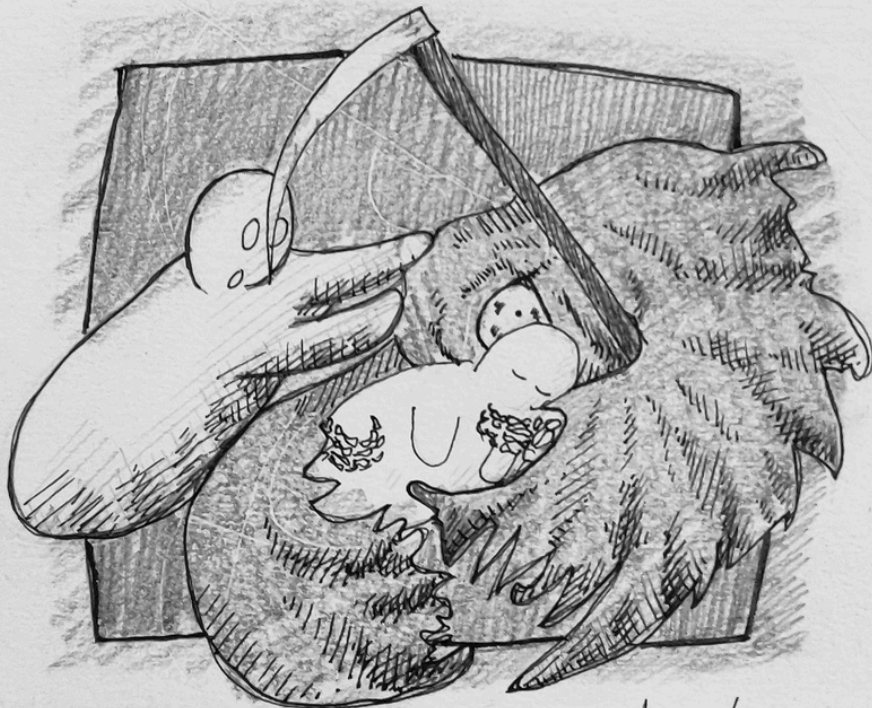


The Language

The language we use matters to family carers.

Often, they are uncomfortable with the word 'carer' or the term 'learning disability'.

The language feels 'professional' and does not capture the deeply entangled and loving relationships they have with a family member.



We watch as those we love die from
abuse and neglect in all it's most
subtlest forms

The Fear

Family carers describe living in a constant state of fear. Families can feel threatened by the power professionals have in this system.

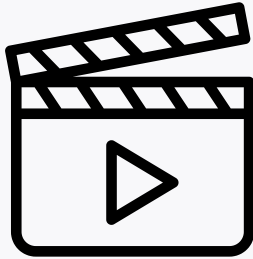
They fear they will be sanctioned by the welfare system. Caitlin described being 'retraumatised every single day' in her dealings with the Department for Work and Pensions (DWP) [1].

“—
I was approaching yet another one of the dreaded assessments and we are always living in fear of them either removing continuing healthcare or worse still, putting her into residential care which I find is emotional terrorism because the best possible situation is what she has now
—”

- Clare, Parent Carer

They are frightened that they may accidentally break the rules leading to the removal of care and support, or the system might take the person they care for away.

Such was her fear and mistreatment, Clare described her treatment by the system as a form of 'emotional terrorism'.



**Watch Clare talking about
'emotional terrorism' here:**



“
| My fears are that I don't have
anyone to take over when I die so
it will be the state. That is the
most God-awful thing I can imagine.
The stuff of nightmares, I can't go
there. I can't explain it to my
daughter as she has no reference
for death. That's awful, that one
day I won't come to her anymore.”

- Kate, Parent Carer

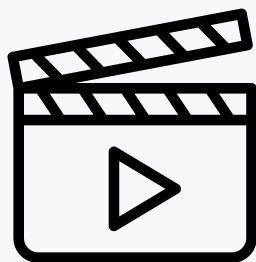
The constant fight for support in the present, makes families fear for the future, when they are no longer there to advocate.

The Lack of Understanding and Knowledge

Family carers feel that the work they do is unseen and misunderstood by the services who should support them.

They feel support services do not understand how family carers' sense of happiness and wellbeing is closely linked to how the person they care for is feeling.

Often family carers seek mental health support as a last resort. This is often because they do not believe their experiences will be listened to or understood by professionals. And they do not believe that there is appropriate support available.



You can watch Teresa talk about the barriers she faced when she sought support for her mental health here:



The Isolation

Family carers feel torn in different directions when they face the competing demands of caring for family members including for aging parents, and their disabled and non disabled children.

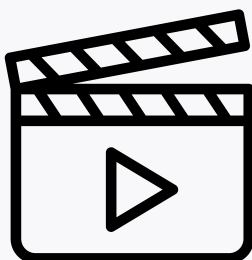
Wider family support networks are sometimes damaged by discriminatory attitudes from family members towards disabled people.

Family carers can become distanced from friends who they feel do not understand, or believe, their experiences of care.

Paid employment outside the family home is impossible for most family carers because of the lack of support.

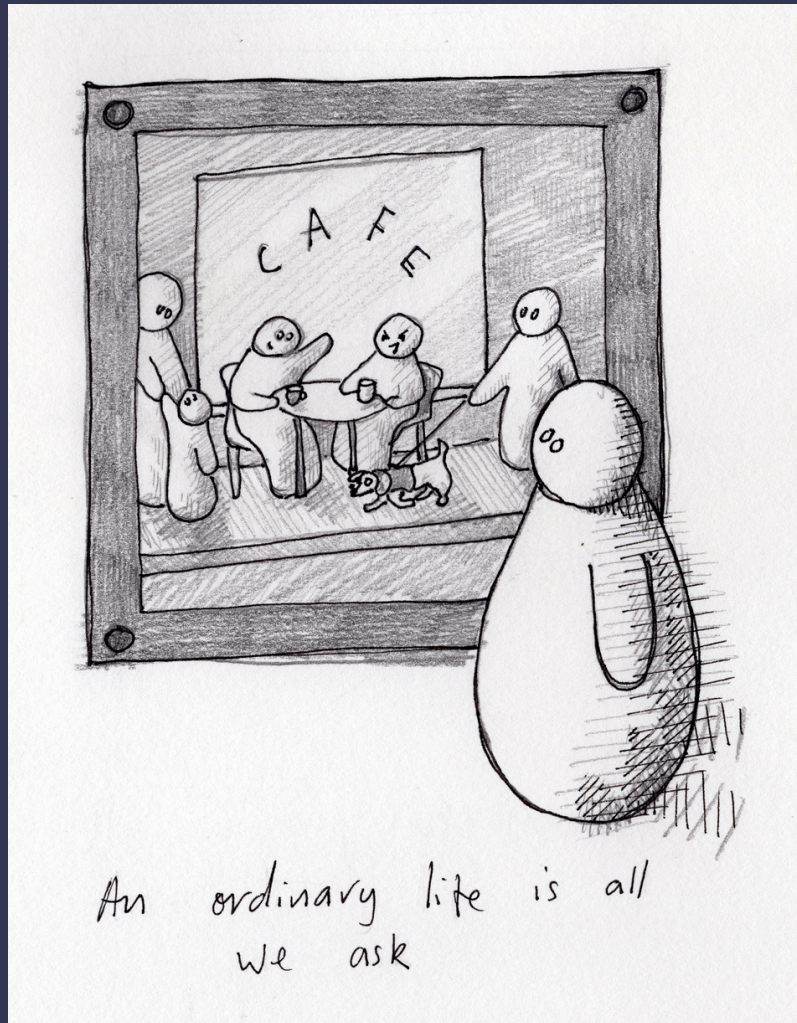
Family carers who do have jobs have to ask for flexible working patterns that fit around their caring responsibilities.

Lack of paid work and part-time working reduces family income, often leaving families reliant on benefits or one household income. The impact of this continues into retirement. Carers allowance is only £81.90 a week and stops when family carers reach pensionable age.



Watch Jemma talk about the isolation she experiences as a family carer here:





Part 1 Discussion points:

1. Has anything in this section surprised you? Why do you think this is?
2. What is your experience of engaging with family carers of adults with learning disabilities?
3. How would you find out that the person you are working with is a family carer of a person with learning disabilities?
4. What ideas do you have for improving the support you offer to this group?



PART 2

The System

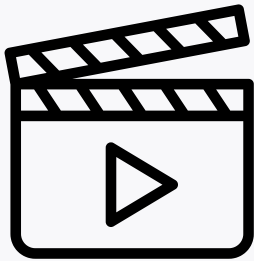
Health and social care systems can act as a barrier to appropriate care and support. They can also have a negative impact on family carers' mental health.

Despite the Care Act (2014) [2], social services are not able to support families in the ways that families are entitled to be supported. Family carers experience assessments as unhelpful, or even hostile.

Family carers don't feel that there are suitable alternatives to the care they provide. They continue to care whether their family member lives at home or somewhere else.

The system fails to recognise that family carers of people with learning disabilities often care over many decades. They often care for a person from birth and continue to do so in a system which fails people with learning disabilities.

People with learning disabilities are excluded from education [3], work [4] and access to health and social care. Poor treatment and low aspirations are tolerated which leads to impoverished and shortened lives [5].



Watch Stuart discuss the challenges he faces to living a flourishing life here:



The constant fight for better lives for people with learning disabilities has a significant and long term impact on family carers' mental health.

Service systems can generate a lack of kindness and be experienced as hostile and abusive to families.

Despite provision under the Equality Act, family carers are often unable to make an appointment with the GP and are not offered reasonable adjustments.

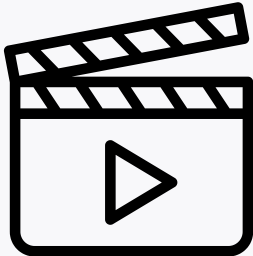
“—
|

[GP] was like 'Oh I've got
somebody else to see after you
so you'll have to hurry up. |

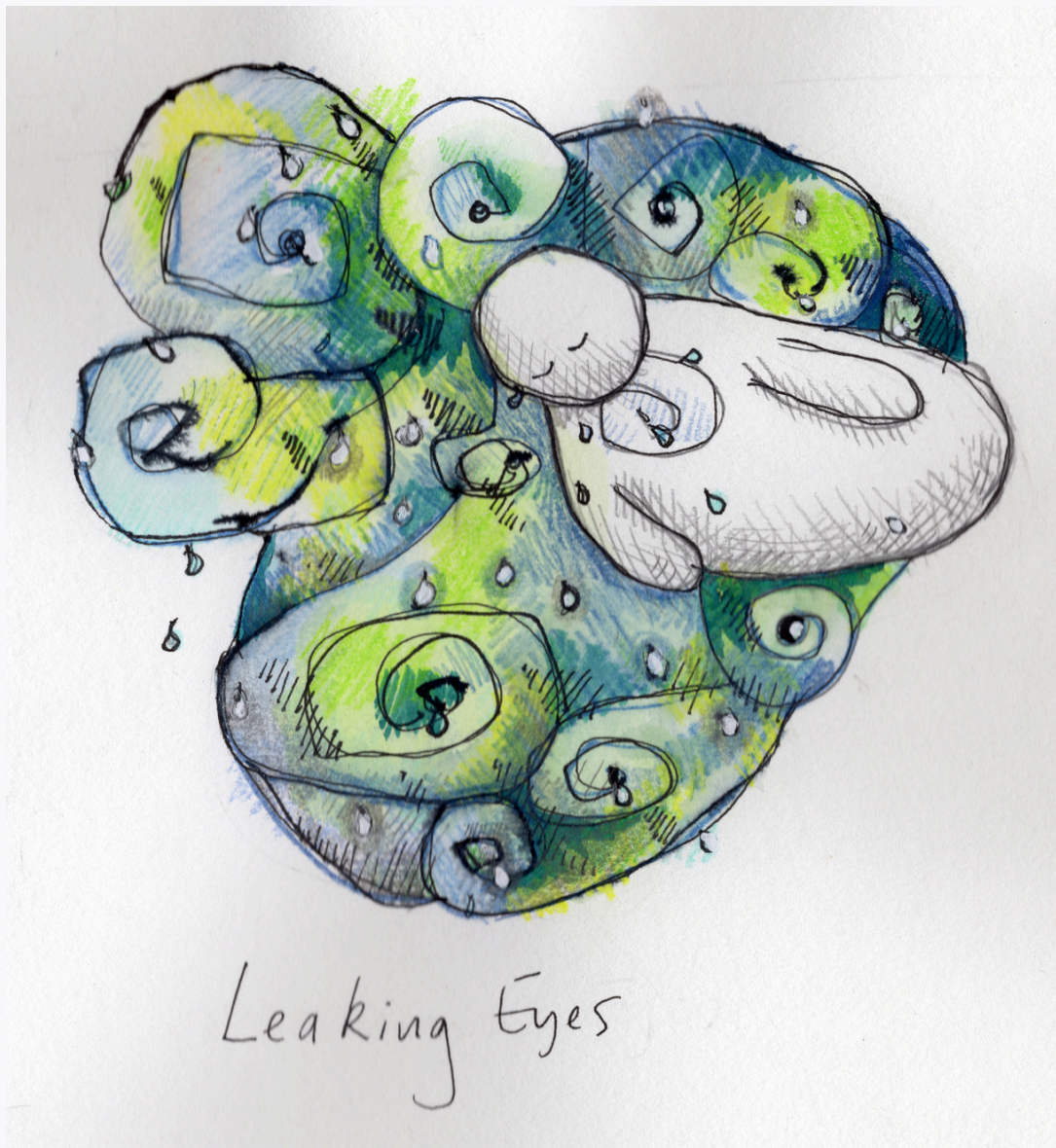
—”

- Julie, Parent Carer

Long waiting lists also deter people from asking for help with their mental health. It is difficult and costly to access therapy privately. Counseling services also fail to make reasonable adjustments for family carers.



You can watch Chris S talking about the impact of the system on his family here:



The Interventions

Practitioners often do not understand family carers' experiences of care and of mental health. This means family carers are offered inappropriate mental health advice and support.

Family carers already know that going for a walk, reading a book or spending time with friends would help their mental health. They simply do not have the time or support to do it. They are frustrated by the offer of 'yoga' or 'aromatherapy' vouchers that they cannot use.

Psychological therapy is often inaccessible or unhelpful. Cognitive Behaviour Therapy (CBT) does not allow family carers time and space to share complex experiences. Many carers cannot find the time to do 'the CBT homework'.

Family carers can be offered mental health medications with no acknowledgement of the long term exhaustion and stress of fighting for services and support and for caring without a break.

They are offered medication when there is no access to talking therapies.

Some carers fear taking medication because they need to be alert to effectively care.

The support of other carers is important. It was described as ‘therapy in itself’, however, this support is not always easily accessible and not all carers feel welcome or included in these spaces.

Some sibling carers told us that they did not meet other sibling carers until adulthood and some would have liked to have met someone earlier.



Part 2 Discussion points:

1. Can you think of any processes embedded in your surgery system that could perpetuate some of the problems outlined above?
2. Do you think you know if suggested interventions such as social prescribing or referral to CBT is helpful for patients? How would you know this?
3. How much attention do you pay as a surgery to your family carer patients? What, if anything, has worked to help this group?

PART 3

What could help Family Carers

- A holistic approach - experiences of caring are always relevant to discussions about the mental and physical health of carers of adults with learning disabilities.
- Continuity of care - it is important for family carers and for people with learning disabilities to be able to build relationships with practitioners.
- Flexibility - family carers sometimes need longer appointments and appointments that fit around their caring roles.
- Kindness - small acts of kindness really matter. A phone call, a 'how are you?' matter more than you know.

“

I think it's important for people to understand what caring is about. I just don't think people realise how hard it is and I think the more we can have some kindness and compassion from others, then I think it would help everyone really.

”

- Chris, Sibling Carer



You can explore the ways in which family carers' have shared their experiences of caring and mental health on the Tired of Spinning Plates Online Exhibition.

The exhibition can be accessed via the QR code below:





Part 3 Discussion points:



1. Can you think of any small acts of kindness that you have used in your daily practice when supporting family carers of adults with learning disabilities?
2. Can you think about how you can share these and how you can integrate them into everyday practice?
3. Can you identify any other opportunities within your practice for small acts of kindness that would make a difference to family carers?

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For more information about the NIHR funded Tired of Spinning Plates project, please use the QR code below to access the website:



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References

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