**Assessing Carers’ Support Needs**

**Resource C – Practitioner Self-Training Workbook**

**January 2019**

**Contents**

[**1** **Introduction** 3](#_Toc857062)

[**1.1** **Carers engagement** 4](#_Toc857063)

[**1.2** **Definitions** 4](#_Toc857064)

[**2** **Reflective practice** 8](#_Toc857067)

[**2.1** **The importance of reflective practice** 8](#_Toc857068)

[**2.2** **Reflection *on* action** 9](#_Toc857069)

[**2.3** **Reflection *in* action** 10](#_Toc857070)

[**2.4** **Messages for managers** 11](#_Toc857071)

[**3** **Carer context** 13](#_Toc857072)

[**3.1** **Adult carers** 13](#_Toc857073)

[**3.2** **Young carers and young adult carers** 13](#_Toc857074)

[**3.3** **Policy** 13](#_Toc857075)

[**3.4** **Life as a carer** 15](#_Toc857076)

[**3.5** **Carer journey** 19](#_Toc857077)

[**3.6 Supporting carers through the carer journey** 21](#_Toc857078)

[**3.6** **Implications for carer support** 25](#_Toc857079)

[**4** **Collaborative communication** 29](#_Toc857080)

[**5** **Recording** 36](#_Toc857081)

[**6** **Video resources** 39](#_Toc857082)

[**6.1** **Adult carers** 39](#_Toc857083)

[**6.2** **Young carers** 39](#_Toc857084)

[**7** **Case studies** 40](#_Toc857085)

[**8** **Further reading** 44](#_Toc857086)

# **1 Introduction**

This practitioner self-training workbook has been developed by the [Institute of Public Care](https://ipc.brookes.ac.uk/) (IPC) at Oxford Brookes University and was commissioned by [Social Care Wales](https://socialcare.wales/). It is one of a suite of four practice resources that have been written to assist practitioners to assess carers’ support needs.

The four resources are:

* **Resource A – Training Manual.** Guidance for trainers that provides information needed to run formal training sessions for practitioners.
* **Resource B – Training Slides.** A slide pack to assist trainers to develop training sessions.
* **Resource C – Practitioner Self-Training Workbook.** A reflective training workbook for practitioners who have not participated in a formal training session, to read, reflect on and work through to improve practice with carers.
* **Resource D – Practitioner Toolkit.** A number of practice tools in one place so practitioners can select and apply to practice in the context of reflection.

This self-training workbook is designed for practitioners, to support them to carry out good quality carers’ assessments, and to help and guide practitioners in working *with* carers and families to get the very best support possible for them.

This table sets out how to use the four Assessing Carers Support Needs resources.

|  |  |
| --- | --- |
| **Who** | **Resource to use?** |
| Trainers | **Resource A – Training Manual**  **Resource B – Training Slides**  **Resource D – Practitioner Toolkit** |
| Social worker and practitioners who carry out carers needs assessments | **Resource C – Practitioner Self-Training Workbook**  **Resource D – Practitioner Toolkit\***  \*Note to practitioners – Please make sure you have read and worked through **Resource C – Practitioner Self-Training Workbook** and/ or have had formal training set out in **Resource A – Training Manual** *before* applying the tools in practice set out in **Resource D**. |

This self-training workbook, **Resource C,** provides material to read, reflect on and work through to improve practice with carers. It explores the context for carers, introduces applicable theory for social work with carers, collaborative communication, recording and provides written and video resources to support practice. Throughout there are exercises to work through and reflect on. **Resource C** will make reference and links to **Resource D – Practitioner Toolkit** and can be used by practitioners as a self-training aid and/or used with and worked through with colleagues, including managers. It can be used as part of wider Continuing Professional Development (CPD) activities.

Below is a key that is used throughout all four resources:

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|  |  |  |  |  |
| Link to video resource | Link to materials from other publications | Tools created by IPC for this resource[[1]](#footnote-1) | Reflective Exercise | Case Study |

The focus of ***all*** four resources are how assessments can be carried out in a way that promotes carers’ well-being, enabling them to support those they care for. Assessments are a real and powerful lever for not only improving carers and families lives but can also influence wider change.

## **1.1 Carers engagement**

Carers’ organisations across Wales helped with the development of the resources. They advised on the content and were also involved in the editing process. Practitioners were also asked to comment on the resources, so the key people who will use them, carers and families and practitioners, have actively shaped them.

## **1.2 Definitions**

Under the Social Services and Well-being (Wales) Act 2014 a carer is *"A person who provides or intends to provide care for an adult or disabled child."[[2]](#footnote-2)*

If a person is caring via a contractual arrangement and/ or voluntary work they are *not* a carer under the Social Services and Well-being (Wales) Act 2014. However, the local authority can ignore this and carry out a young carer’s need assessment if they think it would be appropriate [[3]](#footnote-3). A person is *not* a carer if they are in prison, youth detention accommodation or have been convicted of an offense and residing in approved premises.

A carer is **anyone** who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support*[[4]](#footnote-4).*

An adult carer is a person who is aged 18 years old or over and a young carer is under 18 years old.

### 1.2.1 Assessment

*Local councils now* ***must offer*** *a carers assessment to any carer where it* ***appears to the council that the carer may have needs for support.*** *This is an important change, as previously a carer could only request a carer’s assessment[[5]](#footnote-5).*

An assessment is a process that establishes, *with* the carer and relevant others (such as possibly their family and/or advocates) their needs for support, how their well-being can be promoted and outcomes met. It is usually face-to-face and depending on the situation and individuals involved may take place over a number of visits. The Assessment Form is a product of this process. The assessment form should result in an agreed understanding of what the ***situation is and how well-being can be promoted.***

### 1.2.2 What matters conversation

These resources regard the “what matters” conversation as a skilled conversation, as part of the assessment process. It refers to a *skilled way of working* with carers and their loved ones to establish the situation, their current well-being, what can be done to support them in their caring role and what can be done to promote their well-being and resilience for the better. It is *not* an assessment in itself, it is a way of carrying out the assessment, having the *right type of conversation* with carers and families to establish how you can work with them to support them in good and meaningful ways. A “what matters” conversation is a co-produced interaction between the carer and the practitioner(s) to establish a shared understanding of the situation.

We will consider how you *craft* a skilled conversation before, during and after an assessment so you can then move on to what can be done in terms of meeting needs and outcomes by putting in place arrangements to promote well-being such as services and/or other arrangements.

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| **A skilled conversation** |  |
|  | ***A what matters conversation*** refers to a skilled practitioner conversation that starts right at the very beginning of ***any interaction with the carer.*** From the front door right to the closure stage. |

To be clear; a what matters conversation IS a skilled conversation that occurs throughout the assessment process. Let’s look at what a good skilled conversation looks like and conversely what a not-so-good skilled conversation looks like.

A skilled conversation (a what matters conversation) which forms part of the assessment SHOULD:

* Recognise that every person and situation is unique
* Seek to help the carer think and reflect on what ***changes*** may need to happen to promote their well-being
* Be about ***real listening*** and ***reflection***
* Be filled with ***good intent, respect*** and ***kindness***
* Craft good questions and helps the carer explore possibilities
* Explore ***all the areas of well-being***
* Draw on ***people's strengths and capabilities***
* Consider and work through ***barriers and risks*** in a positive way
* *May* range from one to several conversations and over time.

A skilled conversation (a what matters conversation) which forms part of the assessment SHOULD NOT:

* Be a way of finding out a person's ability to care
* It is NOT a financial assessment
* It is NOT a vague conversation it MUST be a skilled conversation and result in an agreed understanding of what the ***situation is and how well-being can be promoted***
* It is NOT a gateway to a fixed menu of services or a gateway to ‘no further action’ (NFA), it is an ***agreement of how well-being can be promoted*** (regardless of how well-being outcomes may be met).

*Responsibility for well-being must be shared with carers who need support. Persons exercising functions under the Act must empower people to contribute to achieving their own well-being with the appropriate level of support and service. Agencies and organisations cannot deliver a personal outcome for a person, but they can support them to achieve that outcome. Working in partnership with people will be key to securing their well-being and preventing the development of people’s needs for care and support[[6]](#footnote-6).*

# **2 Reflective practice**

Throughout this reflective training aid we will pay close attention to *reflective practice.* Reflection produces thoughts, ideas, connections and insights into what is happening, what the situation is, what is working well, what’s not working so well and why; what can be done differently, and how.

Reflection can happen in two main ways[[7]](#footnote-7):

* Reflection ***on*** action – when you reflect and think back on something that has happened
* Reflection ***in*** action – when you reflect and think about something while you are doing it.

## **2.1 The importance of reflective practice**

Reflection is something that should happen in *every* interaction between practitioner and carers. Reflection helps you see each individual carer and your interaction with them as unique rather than simply going through the motions of a carers’ assessment as a process. Practitioners need to be in touch with these thought processes to prevent the dangers of doing the same things repeatedly despite every carer being unique and different from one another. Reflection is at the heart of a what matters conversation. Reflection is your guide through the complexity and uniqueness of *every* carers situation. Reflection enables you to see your own role and impact as ‘helpers’, ‘professionals’ and ‘practitioners’.

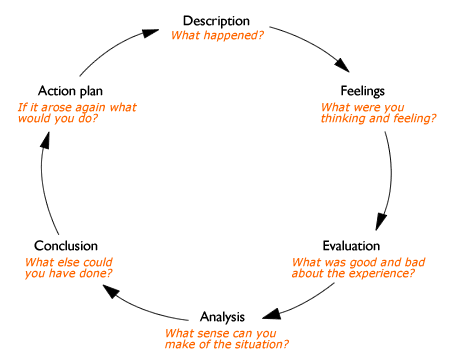
These two elements of reflection (***in*** and ***on*** action) are fundamental to good practice and self-efficacy. Reflection is at the centre of ***all*** of the resources **(A, B, C and D)** in this suite of materials. Reflection will not only underlie the approaches, models and tools but ***all*** the exercises will require you to go through a reflective process of thinking. If you adopt reflection as part and parcel of your practice with carers and care recipients, you will always be learning and thinking about how to do things better – in this respect it can bring about truly transformative results not only for the people you work with but for how you develop as a practitioner.

## **2.2 Reflection *on* action**

The Gibbs reflective cycle (1988) is a useful model to help frame reflective thinking when you are reflecting ***on*** action and we will use it throughout the toolkit. [www.brookes.ac.uk/students/upgrade/study-skills/reflective-writing-gibbs/](http://www.brookes.ac.uk/students/upgrade/study-skills/reflective-writing-gibbs/)

The Gibbs model takes you through a reflective cycle of the **description** of the encounter (‘what happened?’), **feelings** about the encounter (‘what was I thinking and feeling?’), **evaluation** (what was good and bad about the experience), **analysis** (what does the experience mean?), **conclusion** (what else could I have done?) and **action plan** (what might I do differently next time?) This model has stood the test of time and is still used to aid reflection in social and health care as well as other disciplines such as higher education.

**The Gibbs Reflective Cycle**



## 

## **2.3 Reflection *in* action**

A useful model to use when reflecting ***in*** action is the Institute of Cultural Affairs ORID model which is a reflective method of conversation[[8]](#footnote-8).

ORID stands for the process of being objective, reflective, interpretive and decisional. The table below explains what each of these categories mean:

**ORID**

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| --- | --- |
| **Objective** | The practitioner builds up a picture of the situation of the carer and cared for – this includes factual evidence, sensory impressions and objective information. |
| **Reflective** | The practitioner explores with the carer their emotional and intuitive responses to the situation. The practitioner also reflects on their personal reactions, associations they make with the situation, emotions that come to the surface and images in their own mind. |
| **Interpretative** | How the practitioner makes sense of their observations and reflections with the carer – trying to reach a shared awareness and meaning with the carer, looking at possible options and possibilities. |
| **Decisional** | Developing a shared opinion on the situation and deciding ways forward – resolution, action and future next steps/action plan. |

## **2.4 Messages for managers**

If reflective practice happens well it can provide well thought-out and intelligent social work. It encourages constructive thought processes for practice; it can enable rational and emotionally intelligent thinking and be genuinely responsiveness to the carer and those cared for. It is a fundamental preventative approach, as it provides frameworks to explore relationships and strengths rather than starting off conversations with the mindset of ‘putting in services’. However reflective practice can be criticised on two levels, firstly it can be considered overly indulgent – somewhat navel gazing – in a time when pending lists are long and social workers are having to prioritise competing needs daily. Secondly it can be considered to take too much time when social workers just need ‘to get on with the job’. These critiques are reasonable, and managers will have heard these sentiments before or even expressed them themselves. It would be disingenuous to ignore these valid arguments. However, there are key things managers can do to encourage reflective thinking *as a team and within the team.*

* **Introduce and/or remind your team of reflective cycles as a framework for thinking *in* and *on* action.** Make them part and parcel of practice. This can be done in team meetings, supervision and thread through any training or practice resources. For example, they can be used alongside appraisals and personal development initiatives.
* **Practice what you preach.** To enable your team to be reflective, team managers should lead by example and be reflective themselves. Try using reflective models with your team, in panel meetings or meetings with senior managers or strategic staff. ‘Manage upwards’ the message of reflective practice.
* **Be realistic and more flexible about the time good social work and reflective practice takes.** If we are going to be preventative and work within the spirit of new legislation we must accept that time is needed to be invested in the assessment process. An assessment process that takes account lives of individual carers and their families, fluctuating needs and the carers journey. Like any preventative approaches the investment in good engagement and intelligent ‘down-stream’ working will hopefully produce savings long term and more importantly enable better lives for carers and their families.
* **Be confident in supporting social workers to have time to do good preventative work.** This may take considerable skills and confidence in ‘managing upwards’ for example using good negotiation techniques and supporting evidence-based approaches to interventions for example being confident to use testimonials, anecdotal, statistical and formal evidence as well as using analogical reasoning and hypothesis to support evidence and decision making.
* **Build in good habits** of reflection *in* and *on* action.
* Reflecting *in* action is a good habit to get in to and it becomes the basis of good collaborative social work. Like any good habit, the more a person practices it the more it becomes a way of working.
* Reflection *on* action is a useful way to learn from past practice. It can be built into the fabric of your teams such as supervision, team meetings, training, peer learning and action learning sets (ALSs).

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| **Reflective exercise** |
| A really simple way to build time for reflection *on* action is to give yourselves 5-10 minutes at the end of the working day to reflect on a particularly challenging management issue (whatever it may be) and use a reflective framework to help with your thinking. Over five days this equates to 25 minutes or 50 minutes of reflective thinking time – it carves a small but potentially transformative space in your working week. Try it – see how it goes – if it’s a positive experience share it with your team. They might likewise benefit from it. Carving time in your diary for reflective practice is also part and parcel of looking after your own well-being. |

# **3 Carer context**

## **3.1 Adult carers**

Families, carers and their immediate communities provide the foundation of care and support for people living at home who need assistance and are often (although not always) frail, sick, disabled or vulnerable. There are at least 370,000 carers in Wales, but it is likely to be more because this figure is based on people self-declaring themselves as carers in the census. 60% of carers are aged 50+, 49% work and care, and there will be a ***40% rise in the number carers by 2047***. Unpaid carers save the state the equivalent of £8.1 billion in Wales each year[[9]](#footnote-9).

The Parliamentary Review of Health and Social Care in Wales has acknowledged the huge economic contribution that Wales’s 370,000 carers make to the Welsh health and care system[[10]](#footnote-10). Wales has the highest proportion – at 12% – of carers in the UK (more than in any one region of England), and the highest proportion of older carers and of carers providing more than 50 hours’ care a week.

## **3.2 Young carers and young adult carers**

Estimates from the census show that there are 7,500 young carers under 16 and 21,000 between 16-25 hence there are approximately 30,000 carers under the age of 25 in Wales. According to the 2011 census, ***Wales has the highest proportion of carers under 18 in the UK***. Research suggests that the number of young carers aged under 16 is likely to be four times greater than the 7,500 figure because of under-reporting. Young carers may not recognise that their role within the family is different to other children and young people, but they often carry significant physical and psychological burdens. Young carers often have little or no “me time” and can appear to lose their childhood. Young adult carers are four times more likely to drop out from Further Education (FE) and Higher Education (HE) and are two and a half times more likely to not be in employment, training or education. Young adult carers are less likely to be identified and supported than other carers and have higher rates of poor mental and physical health than the average young person.

## **3.3 Policy**

The Social Services and Well-being (Wales) Act (2014) gives carers of all ages living in Wales the same legal rights and entitlements as those they care for. Local authorities have a duty to offer assessments and support plans for carers, developed with them as equal partners, and with the goal of enabling carers to live the life they want to achieve. It reflects the principle that carers, if effectively supported, provide a preventative service, enabling people who are frail, vulnerable or have long-term conditions to stay living at home longer and as members of their local communities.

With carer representatives from health, local government, the third sector and carers themselves Welsh Government have agreed three national priorities to improve the lives of carers. These priorities replace and build on previous work such as the Carers strategy for Wales (2013-2016).

* **Supporting life alongside caring –** All carers must have reasonable breaks from their caring role to enable them to maintain their capacity to care, and to have a life beyond caring.
* **Identifying and recognising carers –** The need to improve carer’s recognition of their role and ensure they can access the necessary support.
* **Providing information, advice and assistance –** It is important that carers receive the appropriate information and advice where and when they need it.

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| **LightbulbReflective exercise** |
| **This reflection exercise can be done privately by practitioners. As a trainer you can facilitate this exercise by allowing about 15-30 minutes on each scenario. The longer you give the reflection, the more powerful it tends to be for practitioner learning.**  Have some quiet time, try to be honest with yourself and ‘sit and be’ with the emotions or feelings that may arise. It can be quite powerful to write or record your reflections, so you can see it in black and white or hear it. Taking it out of the mind makes the reflection more real and practical to *apply* in practice. However, remember to keep things confidential!  **Positive scenario**   * Think about a time when you felt positive about engaging with a carer/or family? * What was your attitude? * How did it affect your behaviour? * How do you think it impacted or influenced the carer feelings? * How did it affect their behaviour? * Do you think it helped with the quality of the supportive/helping relationship? * In what ways? * How could you repeat the success with other carers? * Anything you’d do differently in the same type of situation?   **Negative scenario**   * Think about a time when you felt negative about engaging with a carer/ or family? * What were your attitudes? * How do you think they affected your behaviour? * Do you think it may have impacted or influenced the carer feelings? * Do you think it may have affected their behaviour? * Do you think it hampered the quality of the supportive/ helping relationship? * In what ways? * What did you learn from this situation? * How could you avoid a negative cycle developing in the future? |

## **3.4 Life as a carer**

There is a common reality for carers in terms of the tasks and roles they perform, the emotions they go through and the quality of life outcomes that they experience. Research with carers undertaken by the Institute of Public Care and the Tizard Centre (2017) identified the following common themes:

* **The Scale of the Caring Role:** Carers take on a vast range of tasks that cover every aspect of daily living. For many carers there isn’t much they don’t do either with or for the person they care for. The range of tasks and their complexity means that carers perform multiple roles for the person they care for.

For some carers the nature of their relationship with the person they care for is fundamentally changed by caring for them. It is important to remember that caring can take place in the context of relationships which may be positive, but this will not always be the case. Carers are generally linked to people by bonds of love, friendship and duty but they can also be bound by necessity, guilt and family pressure (Carers Wales, 2018). The shift in roles and the impact it can have on people’s relationships means that ‘being a carer’ affects every aspect of a carer’s life.

The scale of the caring role isn’t just the number of tasks carers are doing or the number of hours they care for. The scale of the caring role is related to the *range* of roles a carer does for the person they care for and the impact this has on the relationship. The enormity of the caring role, the complexity of the tasks involved and the emotional toll of wearing so many hats is exhausting.

* **The Skilled Helper:** The nature of the relationship between the carer and their loved one, means that the carer naturally becomes the skilled helper. This is because they tend to be the person who knows the person being cared for the best. They know the person’s likes, dislikes, what’s important to them, how they like to do things, etc. The knowledge they have about the person they care for makes them very skilled carers. Quite often in the eyes of the person being cared for and professionals the skilled helper is the preferred care option.

The role of the skilled helper can often take-over from everything else resulting in a loss of identity. Being the one skilled enough to help, demands availability at a moment’s notice. For many carers becoming the skilled helper means that they are very restricted in what they can do and when they can do it which results in a further loss of identity. In summary becoming the Skilled Helper is less of a choice and more of a default position that can result in the loss of other roles and a loss of identity.

* **The Hidden World of the Carer:** No one really knows what a carer does because most of it occurs behind closed doors, in the family home. Not only are the tasks a carer performs undertaken out of sight but carers are often over-looked by professionals to the point that they feel invisible. This can mean that the feelings carers experience remain hidden because no one seems be able to really listen to or understand them:

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| *“It’s just such a dark world, you know, the carer’s world is such a dark world because people think they understand but actually until you’re put in that position day in, day out, they have no idea what it’s like to apply yourself in the same situation over and over again.”* |

This can result in the life of a carer becoming increasingly hidden as they isolate themselves more and more:

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| *“You isolate yourself because other people don’t understand.”* |

As the world of the carer becomes smaller and more isolating so can their feelings of desperation increase and there can be a loss of hope for the future:

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| *“…you can’t necessarily see an end point, it’s not like, oh well I’ve only got this for a couple of months and then it will all be okay.”* |

There are also particular ways that the lives of young carers can be affected:

* Missing school or not having time to do homework
* Not going to college or university because they feel they can’t leave home
* Not being able to have friends around
* Not having enough time to enjoy leisure and social activities
* Being bullied at school
* Feeling lonely and cut off from other children and young people
* Not having time to enjoy being young.

It is also important to remember that families are unique set-ups with their own norms, values, beliefs, expectations and way of doing things. Added to this complexity is that family members will also have their own unique way of seeing their family and will interact with the rest of their family in their own individual way It follows then that not *every* person who provides a caring role, within their family, will *identify* as a carer and instead simply see themselves as a ‘mother’, ‘father’, ‘sister’ ‘brother’ or, ‘child’, etc.

* **Sense of Loss:** Initial reactions of parents to the knowledge that their child has a developmental disability often include shock, disbelief, anger, denial and guilt. These emotions are reflected in the initial reactions of families to the knowledge that a loved one has been diagnosed with a long-term chronic condition or terminal illness. These feelings have been described as manifestations of grieving[[11]](#footnote-11). When working with parent carers there is a balance to be struck between avoiding taking a position in relation to disability that is negative and encouraging parents to approach parenting their child positively without minimising the difficulties that they and their child face. Identifying both the factors which can create difficulties and the services and other support arrangements that alleviate the strain and unlock positive experiences is the key. For carers of people with dementia, MS, mental health conditions or survivors of stroke it is often the loss of the person they once knew, loss of the person’s potential, loss of the shared relationship or lifestyle they previously had. Carers also describe a loss of meaning in life due in part to the disconnection between how they expected and wanted life to be versus how it has turned out. This fits with the assumptive world theory model of grief that suggests we each have a life narrative, a personal world. Grieving can turn our personal world and assumptions of what would be in the future, upside down[[12]](#footnote-12).

This grieving process may be experienced as cyclic with symptoms of grief being reactivated with specific triggers and at key moments. Many parents of adult disabled children state this can occur at key transition points in their child’s life. The concept of ongoing grieving is something other carers also report, for example carers of people with Motor Neurone Disease describe it as: ‘*a series of losses’.*

|  |
| --- |
| *“You live with grief, you know and although that gets easier over time it’s always there because you’ve got to mourn the child that isn’t what they should of been or if it’s an acquired you know caring needs that you’ve got you know you mourn for the whole person that you’ve lost and that’s ongoing because you can’t put it to bed and say goodbye because they’re there with you every, every day of your life…”* |

* **Love and Reward:** Until recently, caring was thought to result in negative emotions only. However, recent research has started to recognise that caring is not only associated with negative consequences, but that carers also experience positive gains and emotions. Carers state that caring can increase their feelings of pride in their ability to meet challenges, improve their sense of self-worth, lead to greater closeness in relationships, and provide an enhanced sense of meaning about life and relationships.
* **Mixed Emotions:** It is clear from the research that carers feel a mix of emotions at any one time and live through positive and negative experiences on a regular basis.

*“It was not that they did not grieve the loss of the individual or relationship they once had, their focus had simply moved from thinking of what was lost, to cherishing what remained”[[13]](#footnote-13).*

*“The positive impact of a disabled child on family members occurs concurrently with, and is independent of, any negative impact”[[14]](#footnote-14).*

This fits with Lois Tonkin’s (2007) Circles Model of grief. Her model of grief suggests that the grief does not always diminish, that it can stay the same forever. The loss becomes part of who the person is, but they also grow round their grief, finding new strength of character, understanding and self-esteem[[15]](#footnote-15).

The available evidence suggests that caring has different effects on different people and there is variability in the type and intensity of positive and negative emotions experienced by carers.

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| --- |
| **Video resource** |
| For more information about carers (including young carers and young adult carers) and a PowerPoint with video clips about how carers feel, [click here](https://socialcare.wales/hub/hub-resource-sub-categories/young-carers-and-young-adult-carers). |

## **3.5 Carer journey**

Coming to terms with a caring role can be a long and painful process that requires a huge emotional adjustment. There is a need for a ***detailed understanding of the way caring changes over time, in order that services can provide the appropriate support at the most appropriate time****.* There are a few models that attempt to describe a carer’s journey (Prussell, 1994; Cavaye, 2006). The one below is based on Cavaye’s model that originally had nine steps but for the purposes of this toolkit the journey has been condensed into six steps[[16]](#footnote-16).

|  |
| --- |
| Doing it  Adopting the role  Ending and moving on  Dawning realisation  Adapting it  Struggling with it |

This model reflects the evolutionary process of family caregiving. Some stages overlap with each other and the time taken to reach a specific stage varies depending on individual circumstances. Similarly, the time spent in any one stage varies, and in some cases, carers may bypass a particular stage altogether. It is also important to remember that the mix of positive and negative emotions at every stage will vary for every carer.

* Dawning realisation refers to the process by which carers gradually become aware of how the caring role either is or is going to impact on their own lives. For some this happens gradually and in sync with a gradual increasing awareness of their relative that they need support. For others, whose caring role may begin very suddenly, dawning realisation tends to happen after an initial period of shock.
* Adopting the carer role refers to the carer’s approach to the caring role depending upon how willing and able they are to undertake the variety of tasks that the role encompasses. This is the point at which carer’s often need good support to help them talk through what aspects of the carer role they do feel willing and able to do and which aspects they don’t.
* In many cases carers at the start of the doing it stage are often unsupported by formal service provision and are often hidden from service providers. This is because even when carers acknowledge a need for assistance they do not necessarily want to perceive themselves, or be perceived as someone who needed, sought and received assistance. During this stage carers often become competent and proficient in caring for their family member because they are doing it, largely alone.
* Struggling with it captures the ebb and flow in carer’s perceptions of whether they are coping or not coping with the demands of caring. It is often during this stage that carers finally seek assistance and attempt to access support, often prompted by a crisis of some sort.
* Adapting it reflects the stage in which carers once again adapt their own roles and behaviours to meet the needs of the person they are caring for thus allowing them to continue caring. It should be noted that carers can go around the cycle of doing it, struggling with it, adapting it for some time, possibly years.
* Ending and moving on refers to the stage when carers, for whatever reasons, are no longer providing care. In this final stage of the carer journey, carers experience a mixture of emotions. Feelings of sadness are often tinged with relief but interspersed with guilt at feeling relieved. Others experience overwhelming grief and for many the end of caregiving leaves a huge void in their life that they struggle to move on from.

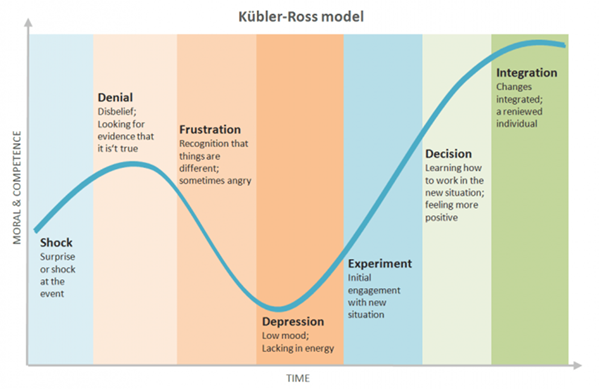
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| **Case study example: Identifying as a carer[[17]](#footnote-17)** |
| **Mary**  Mary has been caring for her husband with Parkinson’s, and her son who has mental health issues for around 10 years, but only identified herself reluctantly as a carer more than eight years ago when her son was first hospitalised and health professionals referred her. She just saw herself as a wife and mother.  Caring has been challenging and stressful at times and she had to give up work as a supply teacher – a job she loved.  *“As a supply teacher, I got to choose my hours. But when caring became more demanding and stressful, I turned down work because I just couldn’t get enough sleep or I needed to travel to health appointments.*  *“Only after a particularly bad episode eight years ago when my son Andrew was in hospital did health professionals identify me as a carer and refer me for support. “Caring leaves little time for me so having access to a carers support group and counselling has really made a difference to me.”* |

## **3.6 Supporting carers through the carer journey**

As practitioners, when we work with carers, we will be supporting them through change to promote well-being and achieve outcomes. Change theory and models are becoming increasingly used in practice to help you be *alongside* the carer and their family. To sit with them, understand, work through and support agreed changes.

The Change Curve Model (1969) explores the process of change and the possible emotions that may arise at these curves of change. The theory says that change is an inevitable part of life, and that sitting with this truth and planning around possible change can produce good outcomes.

**Change curve**



The practitioner’s role is to recognise the change curve and how it relates to the carer journey, the possible emotions change may bring and to help the carer move through these curves of change, thus acknowledging that:

* Carers lives are dynamic and changing
* That carers will experience strong emotions through change

For example, if someone is at the beginning of the dawning realisation stage they are likely to be in shock. Shock and denial can last for some time during which the practitioner can effectively support the carer by accepting that and recognising it for what it is. During this stage a good practitioner will simply remind a carer that they are here for them. At this stage a practitioner would not rush in with loads of questions but be tentative, respectful and acknowledge this as a very real stage for the carer. Once a carer has worked though these stages they may move to adopting the role and doing it where they will be more experimental, in which case more questions would be explored and the practitioner could support the carer to engage in experiential reflection.

As the carer journey continues it is likely that the carer will reach a point of struggling perhaps because the care recipient’s condition has worsened. The carer will once again move through the change curve.

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| **Case study example: Carer journey** |
| **Rhydian**  Rhydian is 12 years old and lives with his mother and younger sister. Rhydian’s mother, Alison, has Multiple Sclerosis (MS) which means that some days she cannot walk and throughout the day she can become very fatigued and be barely able to move. Rhydian carries out some caring responsibilities for his mother but he gets fed up and wants his younger sister, Cerys, who is seven years old, to do more. He feels that he has to look after Cerys, making sure she’s had breakfast and gets to school. He gets fed up having to play with her and watch her TV programmes.  Rhydian’s caring duties include some daily household jobs like filling and emptying the dish washer, emptying and taking out the bins, laundry and cooking. He also carries out personal tasks such as helping his mum go to bed earlier if she is having a ‘bad day’ and to use the toilet and change incontinence pads. His mum’s needs can fluctuate in the day and over days and weeks. Alison calls these regular episodes ‘going downhill’ and gets very low and frustrated.  She feels very guilty about the help that Rhydian has to give her, but she has said that social services will only give her two toileting visits a day and a visit in the morning to help getting out of bed and dressed. Recently Alison’s low moods and feelings of helplessness have been more pronounced and are longer lasting than in the past and can last for weeks.  Rhydian takes out some of his frustration with the situation on his teachers and can be verbally and physically aggressive – he has been warned he might get excluded. He has also told Alison that he does not have friends at school and that they call him a ‘freak, ‘weirdo’ and ‘psycho’. Rhydian can become very tearful when he discusses this and can lash out, throwing things around in the house. Recently he has been shouting at his mum and sister. |

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| **Reflective exercise** |
| **First exercise**  Please read Rhydian’s case study that sets out the situation he is in. Think of the Change Curve Model (1969) and Carer Journey Model, and reflect on the following questions:   * Where do you think Rhydian might be on the change curve and carer journey? * How might you approach the whole family, in particular, Rhydian? * What *values* will you need to draw on as a social worker to work with this family to improve outcomes and well-being? * What social work *skills* will you need to use to work with this family to improve outcomes and well-being? * How might you look after your own well-being when working with this family?   **Second exercise**  Think about a family you are currently working with that has a family member or close friend as a carer(s). Think about the situation and where the family and the carer(s) may be on the change curve and carer journey?   * Had you considered the carer journey before? * Where might you place them on the journey and why do you think this? * How might you check this out further? * How does the carer journey model help you to understand the situation and work with the family to promote well-being? * What works well about this model when thinking of this family and carer? * What not so well? * What will you build on and/or do differently with the family as a result of using this model? |

## **3.6 Implications for carer support**

The support carers say they need is varied and diverse and reflects the range and diversity of the caring role and the people who perform it. Every carer, their relationship with the care recipient and their situation is *entirely* unique. However, recurring themes raised by all carers relate to:

* Rights to be seen, listened to, heard, understood and respected by all
* The need for a good and meaningful assessment
* Adequate information
* The lack of provision of suitable respite care
* The negative impact of caring on work and finances[[18]](#footnote-18).

Evidence shows that good practice in relation to commissioning (at a practitioner and strategic level) can reduce admissions to hospitals and residential care, and delayed transfers of care[[19]](#footnote-19). It can also reduce carers’ needs to access primary care and improve both carers’ health and the health of the people they care for[[20]](#footnote-20).

In a time of austerity smart practitioners will pay close attention to carers, exploring how to sustain caring roles by providing access to support that minimises the burden and maximises the well-being of this population. IPC and the University of Kent have worked with carers and carer centres to develop a Carers Model of Support.

Broadhurst, S. (2019) *Understanding Resilience in Family Carers* (University of Kent: Unpublished)

* Support to navigate their ever-changing relationship with the person they care for.

The caring role is time consuming and exhausting. The nature of the tasks and roles a carer must play and the need to be on permanent standby can be overwhelming. This coupled with any behaviour issues can result in a poor relationship between the carer and the person they care for. As time goes on the nature of the relationship between the carer and the care recipient can also change or may need to change. Navigating these changes for any carer can be tricky as there are often battles with the care recipient along the way. ***Carers are often left with feelings of resentment and dislike alongside feelings of love, guilt and sometimes even despair which all affect the emotional well-being of the carer.***

* Support to manage and cope with the condition(s) the care recipient has and the symptoms they display.

Different conditions result in different symptoms, behaviours and complexities. Different carers will cope with different symptoms, behaviours and complexities to lesser or greater degrees depending on their context, family dynamics and individual personalities. ***Learning what the symptoms, behaviours and complexities are likely to be and potential ways of managing them can be a useful way for carers to increase their ability to cope.***

* Support to maintain their sense of identity past that of carer.

The overwhelming nature of the caring role and the time it often takes means that many carers have to stop doing other activities. This means that the roles they engage in outside of caring reduce. The more their world shrinks, the more isolated they become and the more roles they give up the harder it is to hold on to their own sense of identity past that of carer. Losing other identities is one of the key reasons for reduced emotional well-being. ***Enabling carers to engage in roles outside of their carer role is therefore one of the key ingredients to maintaining their well-being and ability to cope.***

* Empowered to have equal relationships with professionals.

If carers do not feel listened to or involved in the decision making this can have a negative impact on their resilience and ability to cope with the caring role. Definitions of resilience highlight the fact that resilience is not a personal characteristic. The ability to navigate one’s way to resources and support that helps and the willingness of organisations to provide such help and resources has a major impact on a carer’s well-being and ability to cope. ***When carers do not get access to the things that they state will help, their well-being and ability to cope is undermined.***

* Support to navigate and manage the changing dynamics with family and friends.

Caring for a family member can put many pressures on family dynamics. The wider family can be a source of support ***or*** stress as can friends. In many cases carers increasingly isolate themselves particularly at times of stress if they do not have family and friends who listen to them, accept their emotions and their opinion of what will make a difference and are willing to help facilitate this. ***How supportive a carers’ family and friends network is, will impact on the carer’s emotional well-being and ability to cope.***

* Support to ensure the community they live, work and socialise in does not discriminate against them.

Carers want a community that facilitates access to the things they need to keep caring. A community that values their expertise as a carer and recognises that they are often the person who knows the care recipient best. A community that sees them as a person beyond their caring role and supports them in a holistic way to engage in a life that is meaningful to them. A community that supports them to adapt to their ever-changing relationship with the person they care for. ***Creating such communities requires investment in raising the awareness of the issues and challenges carers face.***

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| **Reflective exercise** |
| Think about a carer you have recently undertaken an assessment with and reflect on the following questions:   * What was important to them? * What were their strengths? * What challenges were they facing? * Looking back at the Carer Model of support and thinking about their challenges which aspects of the model of support seem most relevant to their situation? |

# **4 Collaborative communication**

To be able to genuinely work alongside and with carers, practitioners need to develop collaborative communication values, knowledge, skills and techniques. Good conversations as part of a carer’s assessment take real practice skill. It requires the practitioner to conceptualise a conversation, know how it may unfold, what skills they need to employ and techniques to increase the carer’s ownership of the process and eventual outcomes.

Open questions are questions that encourage reflection and thoughtful responses as opposed to closed questions. Closed questions, are questions that can be simply answered by a ‘yes’ and ‘no’. Too many closed questions mean that a conversation can end promptly, and engagement often ends in a conversational cul-de-sac.

* Open questions will ask **how you feel?** *not* **what do you feel?** which is a closed question
* **Can you?** (open question) rather than **where?** (closed question)
* **Tell me** (open question) as opposed to **‘Why?’** (closed question)
* **What do you think?** (open question) instead of **do you?**

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| **Closed questions** | **Open questions** |
| * Are you a smoker? * How many do you smoke a day? * Is your health not too good at the moment? * Are you a carer? | * Would you mind if we talked about your smoking? * How do you really feel about the smoking? * Would you mind if we talked about your health? * Would you mind if we talked about how you are helping your daughter? |

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| **Case study example: Open questions and reflective statements** |
| Carer “*... everyone tells me I must look after myself and take more of a back seat with Jim…”*  Practitioner: *“… it’s not easy for you to take a step back from your role.”* [reflecting]  Carer: “*It really isn’t, I know the worry is not good for me and it keeps me awake at night worrying, what would happen to him if anything happened to me…? I am not in great health you know…”*  Practitioner: *“You can feel the effect on not taking a step back and it’s really worrying to you…”* [reflecting]  Carer: “*That’s right but it’s so hard to let go after all these years…”*  Practitioner: “*It’s difficult for you to imagine not always being there for him…”* [reflecting]  Carer: “*That’s right…”*  Practitioner: *“I am wondering what would be helpful to you… would you mind if together we thought more about this?”* [seeking permission]  Carer: “*I just don’t know… I really don’t…”*  Practitioner: *“How important for you at the moment do you think it is that you take a step back…”* [open question, starting reflection on possible change]  Carer: “*I feel so tired and being around all the time really wears me down…”*  Practitioner: *“On a scale of 1-10 (10 being very important – 1 being not important) where might you place the importance of possibly slowing down or as you mentioned ‘taking a back seat’...?”* [open question, starting reflection on possible change]  Carer: “*Goodness I am not sure – maybe an 8?”*  Practitioner: *“Okay – so about an 8?”* [summarising]  Carer: “*I suppose that is quite important isn’t it?”* |

The below table illustrates the same carer and practitioner – this time the practitioner is asking closed questions, advising, confronting and directing.

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| **Case study example: Closed question** |
| Practitioner: *“Are you a carer?”* [closed question]  Carer: “*Well… I think I am. I have looked after him for years…”*  Practitioner: *“How many hours a day do you provide care?”* [closed question]  Carer: “*I don’t really know… I pretty much do everything.”*  Practitioner: *“With your health problems you are going to get worse, if you can’t take a step back… you can’t continue like this… it’s making you ill.”*  [confronting]  Carer: “*Yes I know but I can’t help feeling this way. I’ve always looked after him.”*  Practitioner: *“But if you carry on like this it’s going to make you really ill and you may not be able to care for him like you have done in the past.”* [confronting]  Carer: “*Yes, I’ll try…”*  Practitioner: *“Well we’ve got some good care agencies that can help you.”* [advising and directing]  Carer: “*Yes okay thanks, I’ll give it some thought, thank you.”* |

You may find it useful to look at the following tools at this point. All the tools can also be found in the accompanying toolkit.

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| **Open questions tool** |
| * Would you mind if we talked/had a chat? * Can you tell me a bit more about what’s been happening? * What bit concerns you most? * In terms of the bit that concerns you most, what would you like to have happen? * What would have to be different for that to happen? * What impact would it have if what you would like to have happen, actually happened? * On a scale of 1-10 where are you now? * What would get you to the next number? * What strengths do you have that will help you? * Who else could help you? * Anything else that could help? * What do you need to do next? |

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| **Reflective exercise** |
| Thinking about a carer assessment you have done or are going to do soon and reflect on the following questions:   * What might be the benefits of using these types of questions? * Is there anything you will need to be mindful of if you use these questions? * What opportunities do you have for practicing or testing out these questions? |

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| **Conversational traps to avoid**[[21]](#footnote-21) |
| **Expert trap –** “I know best” – “Given how tired you are I think you should…”  **Power trap –** “I am the decision maker” – “I think your mum should move to a care home”  **Problem solving trap –** “We can solve your problems” – “We should do this – I think this may make you feel better…”  **Question and answer trap** **–** “I ask the questions you answer” – “How, what, when, why… how, what, why, when…”  **Yes – but trap** **–** “I know better” – “I understand but… I see where you are coming from but…”  **Labelling trap –** “We know you” – “I think you may lack insight” – “I can understand why you would be verbally aggressive in the situation…”  **Confrontational trap** **–** “You are wrong” – “If you carry on like this, the situation is going to get worse…” |

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| **Reflective exercise** |
| Thinking about any carer’s assessments you have done reflect on the following questions:   * Have you ever fallen into any of the conversational traps above? * What were the consequences? * What could you have done differently? |

Listening is a real skill and is needed in every interaction with a carer or family. Our engagement with carers and the carer representatives consistently said that being listened to was important. Listening can build trust, increases disclosure, reduces defensive behaviour and decrease ‘hidden harm’ because it potentially keeps the door ajar to the carer/family which might otherwise remain shut.

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| **The 6 Levels of Listening[[22]](#footnote-22)** | | |
| **Levels** | **Activity of listener** | **Effect on person being listened to:** |
| **1** | **Listening to ‘argue’**  The listener is thinking, “do I agree or disagree with what this person is saying.”  The listener is getting ready to interrupt and put their views across! | Doesn’t feel listened to and doesn’t feel heard or understood – and possibly might even feel undermined. |
| **2** | **Listening to ‘think about your next question’**  The listener is thinking, “what question should I ask next.”  The listener is thinking about the correct ‘formula’ they should be following. | Doesn’t feel listened to and doesn’t feel heard or understood – and possibly might feel the listener is following some sort of training manual! |
| **3** | **Listening to ‘demonstrate you are listening’**  Using eye contact and positive body language to demonstrate you are a good listener.  The listener’s desire to ‘look like a good listener’ is distracting them from effective listening. | Starting to feel that the listener is interested in what is being said – but this feeling will quickly disappear if there is no evidence that the listener has really heard and understood what was said. |
| **4** | **Listening ‘actively’**  Using eye contact, positive body language and accurately reflecting back what the other person is saying. | Feels listened to and understood – feeling that the listener is genuinely interested in what is being said. |
| **5** | **Listening to ‘understand’**  Using eye contact, positive body language and accurately reflecting back what the other person is saying. Mirroring and matching their body language, matching their metaphors and representational systems. | Feels very understood, feels that the listener is interested in what is being said and ‘gets them’ and what it’s like to be in their position. |
| **6** | **Listening to ‘help the speaker to understand themselves’**  Using eye contact, positive body language and accurately reflecting back what the other person is saying. Mirroring and matching their body language, matching their metaphors and representational systems – plus using your own self-awareness and intuition to connect more fully with what the person has said and to accurately reflect thoughts, feelings and observations. | The enhanced quality and clarity of thinking that is generated creates significant insights and ‘light-bulb’ moments.  Feelings of being listened to and understood at a very deep level. |

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| **Reflective exercise** |
| Read the 6 levels of listening tool in the toolkit and reflect on the following:   * Think of when you were operating at each level. * How does this make you feel? * What does this mean? * What needs to happen to move towards level 6?   For example, sometimes a practitioner may feel that they operate at level 2 because they feel that they have a series of questions they must ask and they are thinking about a service that might be able to fit the carer. Whereas the ideal situation would be to listen at level 6 to explore impacts of caring on well-being and what outcomes the carer may want to achieve to promote their well-being.  What needs to happen to move up the levels, in terms of your listening? |

# **5 Recording**

Developing personal outcomes with the carer is a way of creating actionable, measurable targets on the journey towards well-being. Below is an example of the type of outcomes that might be relevant to carers.

|  | **Well-being domains** | **Personal outcomes** | **Link to carer model of support** |
| --- | --- | --- | --- |
| Adult carer | * Participation in work * Physical, mental and emotional health | * I want to continue to work in paid employment * I want to be able to support my husband to move around our house without injuring my back | * Support to have other roles and identities past that of carer * Support to manage the condition and symptoms |
| Young carer | * Education, Training and Recreation * Domestic, family and personal relationships | * I want to go to my dance class with my friends every week * I want to enjoy doing fun things with my Mum not just look after her | * Support to access the community * Support to have a positive relationship with the care recipient |

Outcomes should be recorded according to SMART principles.

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| **Outcomes tool: SMART principles** |
| **Specific** **–** Try to be specific about the outcomes the carer wishes to achieve. For example, “I want to continue my education and will enrol in college” rather than “I wish to continue my education”  **Measurable** **–** There should be obvious way for measuring progress towards outcomes, for example, “Paul has enrolled in college and will start on [date]” “Paul has started college and is enjoying it…”  **Attainable** **–** When people identify outcomes that are really important to them (for example, “being able to go to the gym again and feel healthy”), they are more likely to develop the attitudes and ability to reach them.  **Realistic** **–** Goals should represent an outcome that carers are willing and able to work toward. This, of course, will depend on the individual circumstances of the carer but could translate as “I would like to complete my lifeguard training”; “I would like to feed my mum rather than the carers”.  **Timely** **–** Goals should be grounded within a time frame “by July, I will have enrolled in college”, “by the end of next week, I will be feeding my mum”, “by April, I will train as a lifeguard”. |

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| **Reflective exercise** |
| Look at the personal outcomes in the table above. How might these outcomes be written using SMART principles?  Think of a carer you are currently working with – what outcomes do they want to achieve to promote well-being?  How do these outcomes link to well-being and the model of carer support?  How might these outcomes look like as statements on a plan?  Write a few down (Hint – these are positive statements that encourage hope and something to aspire to, should be on SMART PRINCIPLES and written in the carers own words/first person) |

In a traditional model of a carer’s assessment, the assessor might think of *one* carer, caring for one person with support needs. However often people’s situation are more complex than this as often the carer is part of a family network that is providing care and support. For example, mutual caring is where the carer and person being cared for rely on each other for support and care. Many carers care for more than one person at a time, for example sandwich carers, where middle aged/older women will look after a parent who is significantly older but also care for grandchildren. Some carers will not live with or near the person with care needs and care at a distance, such as telephoning, using the internet, giving vital support, checking and reassurance and visiting when they can. The assessor should consider the wider family and friends; what roles are people playing; what does everyone in this family need?

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| **Case study example: Sandwich carer** |
| Mrs M is daughter and carer to her mother, Mrs S, who is 92. Mrs S has late stages of Alzheimer’s and Polymyalgia. Mrs M would like her mother, Mrs S to have a good quality of life, to stay in her extra care housing (ECH) for life, despite a low Bartel and MTS (Mental Test Score) ***(Quality of life [well-being] cared for person)***. This means that Mrs S, will require carer visits throughout the day and a hoist amongst other arrangements. Mrs M wants to support her mother but also wants a ‘life of her own’ for example continue going to the Women's Institute (WI) monthly and going to her daughters once a week ***(quality of life [well-being] for the carer)***. Mrs M, with the social worker have agreed that Mrs M will provide certain times for care in between care package visits (she will have an OT and dietician visit to explain how to help mum at meal times). She will have a Wednesday evening out of every month to go to the WI and will visit her daughter weekly – the care package will put in extra visits for these times. Mrs M is also in telephone contact with the local carers centre and the details of support are included in a support plan, with other key telephone numbers and a contingency plan in place ***(Managing the caring role)***. The practitioner and Mrs M agree to see ‘how it goes’ over the next few weeks – Mrs M feels comfortable that she is recognised as a carer, her knowledge and expertise is respected and feels confident to be open and honest with the practitioners ***(process)***. |

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| **Reflective exercise** |
| * Think of some carers you have recently worked with. * What were their strengths and resources? * How would you affirm and recognise their expertise both verbally and in the written form?   For example:  Verbal – I think it’s lovely that you and your mum can both stay up at watch films if you want to together. You were right all along that the care agency visits were getting in the way of your evenings together.  Written – Mary has a very close relationship to her mother, she enjoys her mums company and arranges to have film nights. Mary is very supportive of her mother and brings real positivity to her mum’s evenings. |

# **6 Video resources**

The following are short video clips of carers describing their experiences.

## **6.1 Adult carers**

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| **Video resource** |
| This [film](https://www.youtube.com/watch?v=PucZMauWmMo) shows Muhammed, a gentleman talking about his role as a carer. From Carers Leeds, it illustrates how long he was a carer before identifying himself as one and the amount of care he carried out and still carries out for his family. |

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| **Video resource** |
| Watch this short [film](https://www.youtube.com/watch?v=GAUcDOZBEh4&feature=youtu.be) about Margaret and Susan (mum and daughter relationship – with daughter as the carer) |

## **6.2 Young carers**

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| **Video resources** |
| This [film](http://www.tide.uk.net/join_tide/experiences-stories/rachaels-reflections-story/) is on a young carer talking about her Nan with dementia who she cared for without realising she was a young carer.  In this [film](https://www.youtube.com/watch?v=gAQ9k58fGLg) a group of young carers are in a choir singing about being young carers behind closed doors. |

# **7 Case studies**

Below are four case studies followed by a reflective exercise that you may find useful.

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| **Case study – Carer parent[[23]](#footnote-23)** |
| **Kate**  Kate is a parent carer to her son who is ten years old. He was born with a number of health issues, the primary one being a rare genetic disorder, along with learning disabilities, ADHD, speech, language and sensory issues.  Kate lives with her partner, son and seven-year-old daughter. Her son attends a mainstream primary school but with dedicated one to one teaching support at all times.  Being a parent carer has had a huge impact upon Kate’s life. Due to her son’s needs Kate is unable to work in paid employment as she needs to be flexible. As a family they have had to adapt the way in which they live to suit their son’s needs and have very little time as a couple, as specialist childcare is needed.  Kate says, *“As a parent carer I always feel as if I am fighting for something. There is constantly something that you need to fight for, for your child. Life is a struggle, it’s hard on relationships, my partner and I often argue about how best to meet our son’s needs, or about strategies for best managing his behaviour.”*  *“My wish list as a carer is for there to be less red tape, shorter waiting times for assistance or assessments and more resources for children with care needs. I volunteer in a parent liaison role with the ‘We love carers’ group’ to help other parent carers to understand their rights and to work with organisations to improve services for carers”.* |

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| **Case study – Carer of a son and wife[[24]](#footnote-24)** |
| **Philip**  Philip Wright is a carer and here is his carer story:  *"I have four sons. My 17-year-old, Aaron, is severely disabled with quadriplegic cerebral palsy. My wife Michelle, who shared responsibility with me, nearly died in**2011 with a brain aneurysm and a heart valve replacement. It has affected her left side and she is unable to look after our son Aaron any more. So my 19-year-old helps to look after her.*  *“Aaron needs 24-hour care. I am up most nights and I get no sleep whatsoever. My 19-year-old son looks after Aaron on Wednesday nights, so I can get at least one night's sleep a week.*  *“School holidays can be hell. Aaron doesn't like too much sun, so we tend to stay indoors a lot. I'd like to take my boys out for the day but it's just not possible and I can't expect my eldest son to look after everyone else.*  *“Please don't get me wrong, I get a lot of happiness from my family so don't think it's all bad, but there are some very, very hard times.*  *“I love my family to bits and would do all I can but when you get no time to yourself and never get chance to socialise anymore it has become very stressful and lonely.*  *“I think these tests [screening for signs of depression] would make me feel that my welfare is being looked after which I would like. But what would really help is someone coming to the house to help me and to give me a break."* |

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| **Case study – A recently bereaved carer** |
| **Claire**  Claire is 66 and was caring for her husband, Colin, who had early on-set dementia. Colin has recently died from the disease. Claire, was a nurse, and took early retirement to look after Colin. Towards the end of Colin’s life he required 24-hour nursing care. This was provided in their home with a large care package of two carers visiting four times a day and equipment such as hospital bed and hoist. She was heavily involved in his care and did everything for her husband outside of these carer visits.  Before Colin needed 24-hour care Claire was involved with the local carer groups and was involved in council consultations about caring. However, for the last 18 months her time has largely been spent in their home, only getting out when her daughter visited and when the carers came in, she would walk around the block. Although times have been difficult she actively advocated for Colin to have a support plan at home and for her to take on a huge amount of the caring role.  Claire, since the death of Colin, has become very depressed and has developed agoraphobia and is finding it very difficult to leave the home. Her daughter is very concerned for her and reports that her mum says “*I’ve lost my husband and my role in life – this home has been my universe for years – I don’t know what to do anymore…”* |

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| **Case study – Carer looking after someone with mental and physical health issues** |
| **Terry and Gethin**  Terry, has recently been diagnosed with heart failure (CHF) and clinical depression. Terry is a widower and has one son, Gethin. Before Terry’s heart failure was diagnosed he had been recovering from bowel cancer and radiotherapy. His depression has been long standing and was triggered by the death of his wife five years ago, who had breast cancer. Terry is not known to mental health services but is on anti-depressants.  Gethin lives with his dad and became his main carer during the cancer. He provided personal care and help with domestic activities of daily living such as house cleaning, cooking and laundry, etc. They also had a support package in place with carer and district nurse visits.  Gethin is 21 years old and wants to pick up his education again that he ‘put on hold’ during his mum and dad’s illness. Terry is supportive of this but is also anxious that he will have to depend on others. His CHF is causing him pain, severe breathlessness, poor mobility and compounding his clinical depression. Gethin, wants to continue to support his dad but also ‘have a life of his own’. |

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| **Reflection on your learning** |
| Think about what you have read, learned and reflected on, about doing carers needs assessment, through working through this workbook.  Below are reflective questions based on the same thought processes as the Gibbs (1988) model in (2.1). We would like you to work through these questions and use them to frame your own thinking on your current learning from this workbook and how you may apply it to future work with carers.  ***What did you read and learn about in this workbook?***  ***How did working through this work book make you feel?***  ***What will you stop doing when carrying out assessments with carers?***  ***What will you continue to do?***  ***What will you start doing?*** |

# **8 Further reading**

Critical Thinking & Professional Judgement in Social Work (2015) Rutter, L. and Brown, K. SAGE.

A comprehensive text book on how to do critical thinking to inform good practice judgement for students and practitioners in social work.

Developing emotional resilience in social work (2014) Grant, L., and Kinman, G. Community Care Reform.

Grounded in both theory and practice, this book explores how resilience theory and techniques can be applied to help social workers manage the complexities and challenges they face in everyday practice.

Evidence-based Practice in Social Work (2011) Matthews, I. and Crawford, K. Learning Matters Ltd.

An easy to read and thought-provoking text book on skills to develop around critical thinking and reflective evidence-based practice.

Narrative social work: Theory and application (2013) Baldwin, C. Policy Press

Comprehensive text book exploring the theory of narrative social work and how it can be applied in social work practice. A good introduction to this way of practice.

The Emotionally Intelligent Social Worker (2008) Howe, D. Red Globe Press.

Howe makes a case for the importance of understanding and managing emotions for good social work practice. Written for both students and social care practitioners.

The Skilled Helper. A client-centred approach (2017) Egan, G. Cengage Learning

A detailed text book that looks, in detail, at the micro-skills and practice skills required to be a skilled helper.

The Strengths Perspective in Social Work Practice: International Edition (2013) Pearson A text book exploring both theory and practice of strengths-based practice.

Writing Analytical Assessments In Social Work. Critical Skills For Social Work. Dyke, C. (2016) Critical Publishing.

A good text book exploring critical skills for social work. Looking at chronologies, genograms and ecomaps, planning reporting, writing and analysis.

1. Tools created or adapted by IPC unless referenced otherwise. [↑](#footnote-ref-1)
2. Social Services and Well-being Act (Wales) 2014 [www.legislation.gov.uk/anaw/2014/4/section/3/enacted](http://www.legislation.gov.uk/anaw/2014/4/section/3/enacted) [↑](#footnote-ref-2)
3. Carers Trust: Rights for young carers and young adult carers in the Children and Families Act 2014: page 2. [↑](#footnote-ref-3)
4. Carers Trust Website *About Carers* [carers.org/what-carer](https://carers.org/what-carer) [↑](#footnote-ref-4)
5. Carers Trust Website [carers.org/article/social-services-and-well-being-wales-act-2014](https://carers.org/article/social-services-and-well-being-wales-act-2014) [↑](#footnote-ref-5)
6. Welsh Government (2014) Social Services and Well-being (Wales) Act Part 2 Code of Practice (General Functions) p.8 para 29. [↑](#footnote-ref-6)
7. Schön, Donald A. (1983). *The reflective practitioner: how professionals think in action*. New York: Basic Books. [↑](#footnote-ref-7)
8. [www.ica-uk.org.uk/images/stories/mgilbraith/ToP\_method\_overviews/ToP\_method\_overview\_-\_FC.pdf](http://www.ica-uk.org.uk/images/stories/mgilbraith/ToP_method_overviews/ToP_method_overview_-_FC.pdf) [↑](#footnote-ref-8)
9. Carers Wales (2015) [↑](#footnote-ref-9)
10. Welsh Government (2017). [↑](#footnote-ref-10)
11. Wilson, J. (2014) *Supporting People through Loss and Grief.* London: Jessica Kingsley Publishers. Page 33. [↑](#footnote-ref-11)
12. Parkes, C. (2006) *Love and Loss: The Roots of Grief and its Complications.* Hove: Routledge. Page 30. [↑](#footnote-ref-12)
13. Shim, B., Barroso, J., and Davis, L. (2012) A comparative qualitative analysis of stories of spousal caregivers of people with dementia: negative, ambivalent, and positive experiences. International Journal of Nursing Studies 49 p220-229 [↑](#footnote-ref-13)
14. Griffith, G., Hastings, R., Oliver, C., Howlin, P., Moss, J., Petty, J., and Tunnicliffe, P. (2011) Psychological well-being in parents of children with Angelman, Cornelia de Lange and Cri du Chat syndromes. Journal of Intellectual Disability Research 55(4) p397-410 [↑](#footnote-ref-14)
15. Tonkin, L. (2007) *Certificate in Grief Support: Extending Your Skills in Working With Grieving Adults.* Christchurch, New Zealand: Port Hills Press. [↑](#footnote-ref-15)
16. Cavaye, J. (2006) ‘Hidden Carers’ Edinburgh: Dunedin Academic Press [↑](#footnote-ref-16)
17. This is a case study example taken directly from:

    Carers UK – Missing out. The identification challenge. Report of findings from Carers UK State of Caring Survey. (November 2016: page 9). [↑](#footnote-ref-17)
18. Carers Wales (2015) [↑](#footnote-ref-18)
19. Institute of Public Care (2014) *Commissioning for Health and Social Care* London: Sage Publications [↑](#footnote-ref-19)
20. Carers Trust Wales (2016) [↑](#footnote-ref-20)
21. IPC adapted Emlyn-Jones, R and Thomas, C – Collaborative communication skills (Power Point). Achieving Sustainable Change (ASC Ltd) and Social Services Improvement Agency (SSIA). [↑](#footnote-ref-21)
22. Worth Learning Consultancy – Coaching Training materials [↑](#footnote-ref-22)
23. This is a case study example taken directly from the website of:

    Dudley Carers Alliance – Being a Carer webpage

    <http://www.dudleycarersalliance.org.uk/carers-stories.html> [↑](#footnote-ref-23)
24. This is a case study example taken directly from:

    BBC news website article ‘I was in tears’: Carers tell their stories.

    <https://www.bbc.co.uk/news/health-22493627> [↑](#footnote-ref-24)