

Chapter 7

Pause for thought

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In our introductory section we highlighted two approaches to recovery: medical and person-centred. In medical recovery, we pointed to the importance of symptom reduction and/or containment. In person-centred recovery we pointed to the idea that hope, agency and opportunity are fundamentally important to wellbeing. In this chapter we want to pause for thought about key relationships between hope and hopelessness and positive and negative expectation, and explore how these relate to person-centred recovery and wellbeing for caregivers. In particular, we will look at the way interactions between hopeful and hopeless relationships are influenced by **positive and negative expectations** from the past and how we think about the future for all people in the triangle of care.

These concepts and their relationships to each other are perhaps more complex than we can describe here, and will be different for every person. We are all human beings, subject to a vast range of combinations of emotions: joyful and bleak, mixed and resolved. But we want to suggest that hope has a special *future active* quality when it comes to transforming difficult or hopeless situations in the present. This is particularly relevant for people experiencing mental health difficulties and for services seeking to combat the organisational discrimination associated with negative expectations for people who need support for mental health difficulties. A hopeful orientation towards the journey ahead may also help restore wellbeing for caregivers when negative expectations *from the past* have stacked up. But – and this is crucial – we conclude with the suggestion that, in principle at least, caregivers already bring a level of wellbeing to the activity of caring within the triangle of care. Although the pragmatic case on the ground is often very different, we want to suggest that positive expectations that wellbeing will be maintained within and alongside the activity of caregiving are subtly different in kind from hope for wellbeing in the future. This subtle difference, we suggest, may offer a different orientation towards the question of recovery for caregivers within the triangle of care.

Why is hope important to recovery?

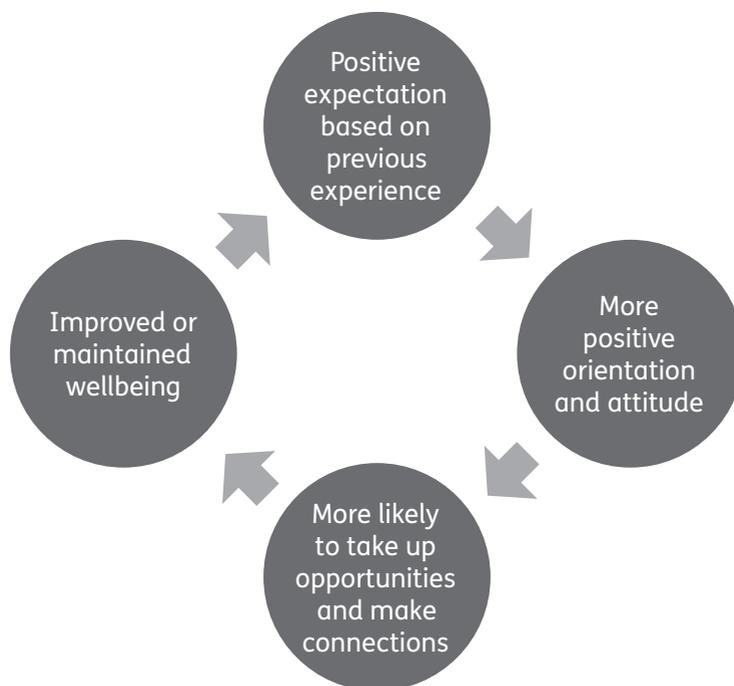
Hope has taken centre stage in personal and social understandings of recovery because, without hope, it is difficult to feel that one can change the current situation or make use of any opportunities to support goals and aspirations. Despite its importance, hope, like recovery, is a difficult concept to pin down. Hope can be for a particular event or occurrence, like winning the lottery. It can also be more general – perhaps a hope for things to improve or be different. Hope is **future-oriented** – you don't hope for something to be different if it is already happening or expected to happen.

Hope is also linked to positive expectation – the belief that a positive outcome is possible. What distinguishes hope from positive expectation is the role of past experience in predicting how likely it is that something positive is going to happen. Ironically, hope is also closely linked to negative expectations from the past. Although this sounds like a contradiction in terms, hope is perhaps most powerful when negative experiences have stacked up, and is closely linked to positive risk-taking. To think about this another way, most people do not expect to win the lottery as the odds look very slim, and most people who play the lottery have more negative experiences of losing their money than positive ones of seeing a return! But the hope of winning structures the everyday actions of millions of people, and may open the door to new possibilities – for example, bumping into a friend on the way to buy a ticket.

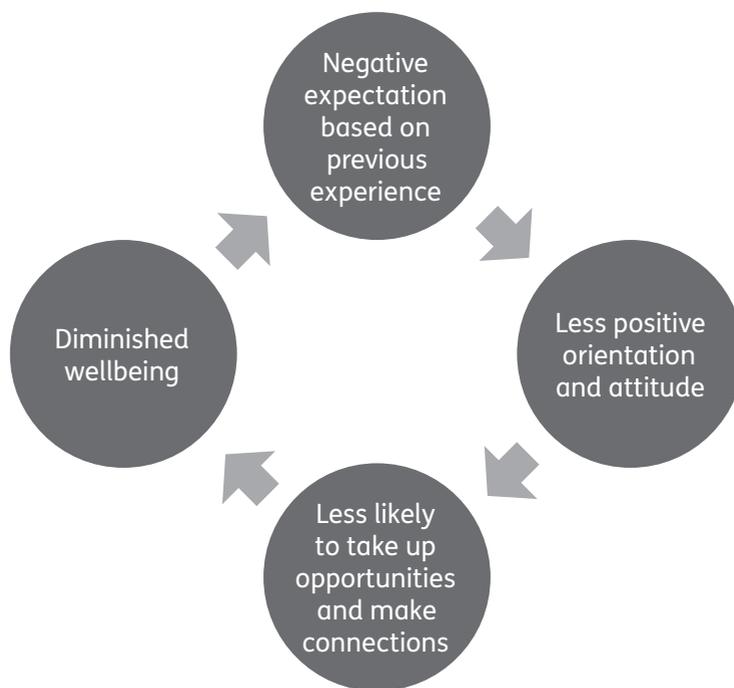
Expectation and wellbeing

How can something as positive as hope be linked to negative expectations? Before we answer that question, let's take a look at how positive expectation supports wellbeing and how negative expectation can undermine it. We base our expectations on how likely we think something is to happen, and this is influenced by past experience. We don't have to hope the sun will rise tomorrow, as past experience suggests that it most probably will – so we expect that the sun will rise tomorrow. People whose past experience contains lots of positive experiences are likely to have positive expectations for the future, and these positive expectations are very important for **wellbeing**. Although most positive expectations are not as certain as the sun coming up, they still influence our attitudes towards present actions and decisions. For example, if, from the evidence of past experience, you expect to enjoy spending time with your friends, you are more likely to make an effort to see

them and to feel confident in their company. Having a strong social network is known to support wellbeing, so these positive expectations of meeting with friends create what might be described as a 'virtuous cycle'. People with lots of positive expectations have very little need to hope for things to be different, as life is likely to be quite good as it is.



Negative expectation works in exactly the same way: if a person has had negative past experiences, they are more likely to hold negative expectations about the future. For example, if, on the evidence of past meetings, you expect your attempts at friendship to be rebuffed, you are less likely to make an effort to meet new people or to try and maintain existing networks. In this way, your negative expectations undermine your self-confidence and potentially lead to isolation, with knock-on negative effects on wellbeing. So rather than a 'virtuous cycle' we get a 'vicious cycle', where negative expectations appear to increase the likelihood of negative outcomes. People with lots of negative expectations may feel more hopeless and think it is inevitable that bad things are going to happen or that nothing will change. They are much more in need of hope because life is not fine as it is.



Hope against negative expectation

It is easy to see how a virtuous circle of positive expectation can support wellbeing and how a vicious circle of negative expectation might undermine it. So how is hope different from positive expectation, and how does it relate to negative past experience? It is important to remember that both positive and negative expectations are merely best guesses about how things will be – they are not facts. So it is not inevitable that negative expectations will result in negative outcomes or feelings. However, the build-up of negative expectation can lead to **false certainty** that things can never change or that negative outcomes are inevitable, and this can be very powerful in influencing day-to-day interactions. The belief that a negative outcome is certain is the foundation for feeling hopeless and powerless to change a situation or too frightened to take any risks. Yet expectations are also not fixed. When you have a positive and perhaps unexpected experience that runs counter to previous experiences, this can offer a small window of **hope** that things will be different and that wellbeing is possible. With hope, you are more likely to interpret past events in a better light and look forward more positively as a

result. And the more hope you are able to hold against the vicious cycle of negative expectation, the more likely it is that you will begin to form positive expectations that support the virtuous cycle of wellbeing.

Read the two scenarios below and try the exercise that follows to get a more concrete sense of the power of hope to work against negative expectation.

Scenario 1

Imagine you are in a desert without any water. All you can see are sand dunes in all directions and you've been exposed to the heat for days. All you can hang on to is the hope of rain or reaching an oasis that keeps appearing miraculously on the horizon. Everything you already know about deserts tells you that rain is very unlikely and the oasis is a mirage. What do you do?

Based on the evidence of past experience (what you already know about deserts), your expectations of survival are most likely to be pretty bleak. If, as would seem quite realistic at this point, your negative expectations pass into hopelessness, the range of action and possibility is limited to waiting for the inevitable, which makes it almost certain you will die. If, alternatively, you hope (quite unrealistically at this point) that there really is an oasis beyond the sand dunes, the range of action broadens to include going in search of it. This search may, in turn open wholly unexpected possibilities and opportunities on the way – for example, by going in search of the oasis, you stumble on a nomadic tribe who give you water and lend you a camel to help you find your way out of the desert. Although the oasis never became a reality, a hopeful orientation towards it widened the real possibilities of action, making a positive expectation of life beyond the desert more realistic on the way. While this example is fictional and somewhat far-fetched, a hopeful orientation in everyday life is often about expanding very narrow possibilities into a present window of opportunity. **Hope has the power to break the hold of hopelessness because it looks beyond the false certainties generated by negative expectation.**

Holding hope for the person cared for

Like positive and negative expectation, hope has important knock-on effects on everyday actions. For these kinds of reasons, mental health services are being encouraged to be more conscious of their role in promoting hope and

their potential to remove hope. In support of this, they are encouraged to work alongside people and, if necessary, 'carry' or 'hold' hope at times of greatest distress while setting personal goals and planning achievable ways to realise them. Retaining and conveying hope can be particularly hard for practitioners who work with people who are at their most unwell. If you constantly see people when they are at their lowest ebb, it's not hard to see how an expectation of poor outcomes and unremitting illness might be set. Perhaps this means there is all the more reason for professionals to rotate between different service settings, so they can see people in different stages of recovery.

Scenario 2

Imagine you are a doctor working in an acute ward. All you see on a daily basis are people who are very unwell. Everything you already know about mental health tells you that medical recovery for these people is very unlikely and holding hope is unrealistic. Jane, one of the clients on the ward, tells you she wants to be a doctor. She has reported hearing voices and acting on their guidance. She left school with no qualifications, but her caregiver tells you she was studying to go to university before she became unwell. What do you say to Jane?

A hopeless response

Based on the evidence of your past experience (what you already know about mental health and your own experience, if relevant, of training to be a doctor), you are quite likely to hold a negative expectation about Jane's chances of achieving her goal. You might assume her voice-hearing experiences are negative and think it would be unkind to hold out false hope, so you tell Jane and her caregiver that her aspirations are unrealistic and should not be encouraged. As a result, Jane refuses to get out of bed and is unreceptive to further efforts to talk to her. Jane's caregiver feels discouraged and does not offer you any more information about how to support Jane back to wellbeing.

A more hopeful response

You ask Jane what she needs to do to achieve her goal, and find out from her caregiver what she does at home that might support this and what stands in the way – not getting out of bed, for a start! You ask the caregiver to find

out what community resources are available to support Jane's dream – extra support at the local college, for example. You ask Jane whether her voices are sympathetic to her ambition or whether they get in the way. Jane tells you that the voices tell her to read books, and get cross when she's slacking. You might still think the chances of success are slim, but by holding hope for Jane it is possible to work on small steps towards her goal, like getting up and dressed and aiming to go back to college when she is discharged. As a result, Jane makes an effort to get out of bed and is keen to talk to you. She brings some notes to your next meeting from her recent studies. Jane's caregiver is encouraged and brings in more information to help you and Jane plan her discharge.

Whether Jane eventually becomes a doctor is not really important in this scenario. What matters is that her opportunities are not reduced by negative expectations of her and that unhelpful assumptions are not made about the positive or negative influence of her symptoms on her future wellbeing. Holding hope in the triangle of care means that opportunities to work towards Jane's wellbeing *in partnership with caregivers* can be acted on as real possibilities, whether the dream is realised or not. Returning to the earlier example of the lottery, most people do not expect to win as the odds look very slim but the *hope* of winning opens the door to new possibilities. Although Jane may never become a doctor, supporting her dream in small steps may enable other supports for wellbeing to come into play, e.g. improving social networks by going back to college. Sharing your hope for Jane with her caregiver and valuing her perspective also supports her to hold hope and take the extra step of accessing resources in the community that could help. If there is hope in the triangle of care, people may put in a bit of extra effort and achieve more than they expected. Future expectations may then be less negative, and the likelihood of future success increases as the vicious cycle loses some of its momentum.

Sources of hopelessness for caregivers

Of course, life is rarely as black and white as the situations we have described above. It is hard for all parties to hold hope when negative expectations have stacked up. The challenge of retaining hope for mental health professionals and the people who come into contact with them is further compounded by the language used in mental health services. It's not hard to see how descriptions of 'severe and enduring' illnesses, 'chronic' conditions and

'disordered' personalities can inhibit positive expectations and hope. Because of their intimate knowledge of the negative experiences and fragilities of the people they care for, caregivers can also hold negative expectations and find it difficult to be hopeful or facilitate activities relating to recovery, particularly if they are fearful of the result.

What you don't want is for them to go back to work and then fail...

Caregivers often question themselves about when to push their loved ones to engage in activities and social life and when to draw back. This can be particularly difficult for parents, who have a lifelong responsibility to maintain the safety of their child. In this respect, hope can be linked to positive risk-taking. In the complex business of 'letting go' and supporting loved ones to take risks (in relation to work, social life, medication use, behaviours, independence), caregivers can experience a range of emotions from fear to guilt to pride.

I'm frightened, I'm almost frightened to do anything apart from, you know, go in and try and chat to him – you know, take some soup in.

It is important not to be judgemental when caregivers identify emotions and behaviours that might inhibit positive risk-taking, as these often need to be owned and worked through in order for alternatives to come into play. Caregivers have testified to the difficulty of positive risk-taking, but also discuss how being hopeful and taking the risk to 'let go' can help loved ones respond differently to the world around them. If one holds hope, it can transform a risk that seems to have only negative consequences into an opportunity that has the potential for positive outcomes. The presence of hope in a situation thus plays a pivotal role in creating positive outcomes for people who experience mental health difficulties, even where this is against a backdrop of negative experiences and expectations.

Exercise 2

To understand these issues in a more personal way, please try the following exercise.

Think of a situation that felt hopeless for the person you care for.
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Why did the situation feel hopeless? Was past negative experience playing an influential role?.....
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Were you expecting a negative outcome?.....
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What would have been an alternative and more hopeful attitude to take into this situation?
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Who/what could have helped the situation to feel more hopeful?
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What outcomes might have resulted from holding a more hopeful attitude?
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If you are a mental health worker, please consider these questions in relation to the people you provide care for. Can you think of any examples where working with caregivers might have helped a situation to feel more hopeful?

Supporting hope for caregivers

Where does hope come from? For people using services it frequently comes from other people, as it is difficult to hold hope for yourself if your experience is very negative. However, it is not so clear how caregivers' hope for themselves and the people they care for can be maintained. Holding hope and allowing positive risk-taking to happen can make for a fraught emotional time, and caregivers often need support in order to manage the process of balancing hope and risk for the person they care for. Where the triangle of care is working well, service providers can be a source of much-needed support in holding hope. Where it is not working so well, however, caregivers are especially vulnerable to feelings of hopelessness for themselves as well as the person cared for, as in the non-fictional situation below.

Scenario 3

It is still really difficult to express how we were affected by this turn of events. We were, or so we thought, a perfectly normal professional family with four happy, healthy, grown-up youngsters all progressing towards or already into adulthood with stable, secure futures ahead. Then suddenly, like a bolt out of the blue, a severe mental illness struck a member of the family...

With my wife approaching retirement I also arranged to retire early. These plans were well advanced when we began to ask what the purpose of this was, as our quality of life at home at this time was really poor.

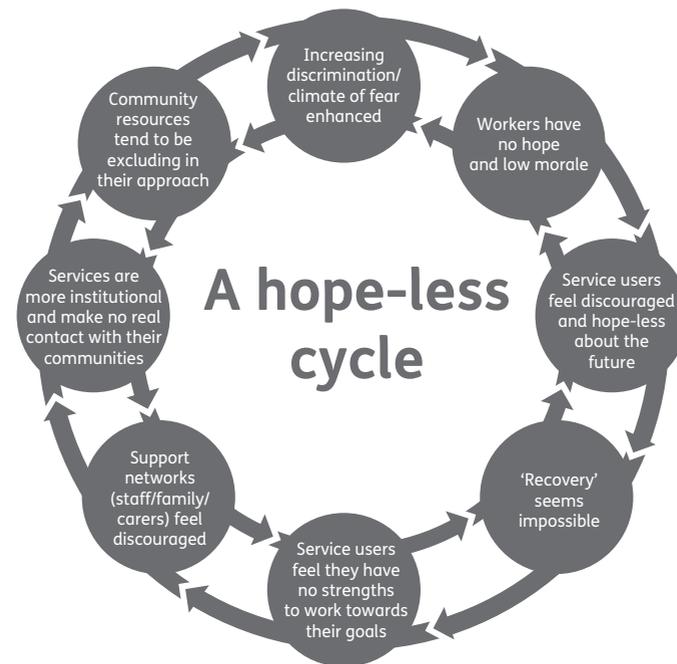
In a few short lines, this caregiver describes a life in which his positive expectations of health and happiness are turned upside down, involving a complex interplay between the loss of an anticipated future and an increasingly difficult home life. It seems pointless to retire because the family has started to believe the situation will never change. Nevertheless, despite the initial sense of shock and loss of quality of life, the author describes how, with the arrival of effective support, he finds

...some recovery in sharing our experiences with others, and helping those in similar situations to ourselves to realise that there is hope.

Looking back, the author also reports that this period of hopelessness reflected both the received stigma about mental health and a lack of support

and information in the early days. Although family wellbeing and quality of life were temporarily undermined by hopeless expectations at this time, the author reports that they were subsequently regained and maintained through better information and support, despite ongoing fluctuations in the mental health of their son.

At a personal level, feelings of hopelessness are part of the human condition and it's not unreasonable for caregivers to hold them when negative experience has stacked up. Organisationally, however, this understanding of hope and hopelessness has far-reaching implications for changing the current position of caregivers in the triangle of care. It is easy to see how hopeless expectations could lead to less resource allocation, less support for people who use services and/or less inclusion of caregivers. In *Travelling Hopefully*, Basset takes this line of enquiry further by suggesting that hopeless services are more likely to lead to socially exclusive and unwittingly discriminatory services, as illustrated here:



Organisational hopelessness can be said to have become explicitly discriminatory when negative expectations are overtly attached to more stigmatised diagnoses, often against the evidence. For example, people who experience psychosis or have a diagnosis of personality disorder are perhaps

more likely to experience discrimination by way of hopeless or negative expectations than people who experience anxiety or depression.

Basset also shows that hopeful services lead to more social inclusion and outreach for everyone in the community, caregivers included.



In other words, hopeful services have the power to combat discrimination based on negative expectation, and have every part to play in making the optimal triangle of care a reality for everybody.

Exercise 3

To understand these issues in a more personal way, please repeat the exercise that was used previously – but this time, think about yourself and your wellbeing.

Think of a situation where you felt hopeless for yourself (e.g. ‘I can’t go on like this’, ‘Things will never get any better’, ‘I will never get a break’, ‘I am never recognised’, ‘I will never have a life of my own’).....
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Why did you feel hopeless? Was past negative experience playing an influential role?

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What did you expect would happen if you put your wellbeing first?

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If your expectation was negative, what would have been an alternative and more hopeful attitude?

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Who/what could have helped you to be more hopeful in this situation (e.g. a friend, relative, fellow caregiver, mental health practitioner)?.....

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What outcomes might have resulted from holding this more hopeful attitude?

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How did you get on with this exercise? It is often difficult for caregivers to put their own wellbeing first, and mental health workers can struggle with it too. If this applies to you, maybe you could ask someone you trust to help you consider the exercise.

Recovery from what?

The approach we have outlined above is a relational one in which hope and hopelessness are part of a spectrum of wellbeing and closely linked to expectation. Like expectation, this understanding of hope is a *belief* about the future that influences the actions taken in the present. It is crucial that what is hoped for is believed to be possible, but hope can still emerge even when the possibility seems very slight. Unlike expectation, hope is oriented beyond

what is believed to be likely, towards imagined possibilities that, like dreams, may not be counted on or even predicted. Everyone has a right to dream and to attempt to realise their imagined futures, no matter how improbable they might seem at the time. For people whose negative expectations have stacked up into hopelessness, hope implies committed action towards possibilities that may present as very unlikely at first but, through small steps, may become positive expectations (or begin to seem more likely) as successive good outcomes stack up.

This returns us to the caregivers' 'Recovery from what?' question. It is entirely appropriate to advocate hope for people who use services, as – bluntly put – there would be no need to use services if levels of wellbeing were already good. However, we also want to suggest that caregivers may start in a different place in relation to wellbeing, which should ideally be something they already have a right to maintain in the triangle of care. As we have shown above, hope is at its most powerful when negative expectations are high. So hope is grounded in adversity – there's no need for hope when things are fine as they are. At an individual level, then, holding hope can be both empowering and difficult for caregivers to do. Yet, as David Harper has recently suggested, it is highly problematic to locate concepts like wellbeing exclusively in individual strength and resilience, as this can implicitly blame those whose wellbeing has been undermined for not being 'tough enough' and deflect focus from social contributors to distress (2012).

The same can be said of hope in person-centred recovery. Without wider social consideration, advocating hope for caregivers can be an insulting suggestion if the weight of their personal experience has been so overwhelmingly negative as to compromise wellbeing. As is evident from the caregivers in this collection, person-centred recovery is frequently a tale of *getting over* interactions that have been based on low or hopeless expectations for the person cared for and/or have not been initially responsive to the hopes and wellbeing of caregivers on their own terms. Should we then be aiming for more than hope as a *corrective* to this legacy of hopelessness and negative expectation? What about supporting caregivers' positive expectations for their own wellbeing early, before they have a chance to be undermined?

We'll revisit these thorny questions in our concluding discussion.