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# Achievements and Challenges for Comprehensive Care of People with Schizophrenia

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I'm grateful for being here and for giving this lecture. I particularly want to thank my colleague and friend Dr. William Lo. I'm going to take you through quite a lot of material. I want to look at some of the achievements and some of the challenges. I think we should be rightly proud – and you should be very proud – of the work you have done and the work the Association has done over many years: 65 years and counting! From the Australian perspective, we take a lot of learning from you about how to do these things and how to give more comprehensive care. One of the reasons I'm particularly pleased to give this talk is that I think you and your association underline how to do this in a very humane and holistic manner.

## Schizophrenia as a complex disorder

We need to remind ourselves that schizophrenia is a complex disorder; in fact it is most certainly not just a disorder but a group of disorders. At the centre is functional impairment. When we talk about function, we talk about things such as vocational function, and it's great that your association helps people to get back into work. We also talk about social function and social integration. We touched yesterday on things like stigma, interpersonal relationships, self-care. Of course the disabilities associated with schizophrenia are not just due to the problems associated with what happens in the brain, but also associated with what society does in response to a person with schizophrenia.

I will use this term 'schizophrenia' – and I know some people find it not very attractive as a term and it carries stigma but it has what we call utility. We know that schizophrenia is often associated with positive symptoms and these are generally seen as the defining symptoms. We are reasonably good at treating those (and I say reasonably because I'll show you some data shortly to say that we're probably not as good as I initially thought). The negative symptoms are the real challenge for us. Treating those symptoms are a major and ongoing endeavour. We often forget this as we have a tendency – and you're better at this than we are in my country where we have a tendency to fall into 'labelling' – to say everything about this person with schizophrenia is because he has schizophrenia. I remember asking some case managers why their patients with schizophrenia do not socialize very much. They looked at me and said, "You are stupid. You are meant to be a professor and you don't even understand that people with schizophrenia don't socialize because they have schizophrenia!" And I said that maybe I am stupid, but I have asked some patients with schizophrenia why they don't socialize and they said, "We don't socialize because we don't have the opportunities. We don't socialize because we have anxiety." Social anxiety disorder is prevalent in a third of these patients. Is this important? Of course it is important because we can actually target social anxiety, therapeutically. We have done trials of social anxiety and schizophrenia using cognitive behaviour therapy. It didn't help their positive symptoms but it helped their self esteem. It helped their engagement with other people. And most importantly, it enhanced

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their enjoyment of life. Life is there to be enjoyed. As Aristotle said, we are social animals ultimately, so if you are socially excluded because of your disorder and your lack of capacity to engage with others, and then you are anxious on top of that, then of course that is a triple whammy. The point I am trying to make is that we really need to draw down to the individual level as to what the particular issues are for that particular person and to help them address these in a holistic way.

**Australians with Psychosis**

Now I'll share with you some data from Australia, which is a rather big land mass just to the south of China and to the left of New Zealand. Some of you have been there. When you come to Australia, you realize the only worthwhile city to visit is Melbourne.

One of the opportunities we had in Australia was to do some good epidemiological studies. A study which was conducted in 2010 (the Study of High Impact Psychoses or SHIP study) gives a snapshot of about 1,800 people with psychotic disorders living in Australia. Australia is a very wealthy country, privileged in terms of services and a capacity to deliver care, but we are still lacking in so many ways. First of all, many Australians with schizophrenia have enduring symptoms. Positive symptoms of psychosis, (delusions and hallucinations), are of course very common in people with schizophrenia, across their lifetime. But what was very striking and upsetting to me in our study was that a large proportion of those people had residual symptoms, ongoing symptoms, and this was despite being engaged with treatment services. What this says is that our treatments are not as effective as we would like and people don't take them as well as they should.

The other thing is that depression and suicidality are very common in the lives of people with psychotic disorders. Lifetime rates are sixty to seventy percent, and current rates twenty to thirty percent. So we need to be aware of this, coming back to my theme about holistic care.

Prof. Eric Chen made the point that some people with schizophrenia only have one episode of psychosis and function very well thereafter, whilst some people have many episodes but function well in-between. Some people unfortunately do not have such a good outcome but this doesn't say we give up on them. We carry on offering opportunities, opening windows and opening doors for them to participate more actively in life and holistic care.

So we have a lot of things to do and a lot of things to try and help people with. Positive symptoms I've spoken about. Negative symptoms and cognitive symptoms, which drive a lot of disability, and the mood and anxiety disorders I have already talked about. Substance abuse, is a very big problem, additional problem. These include cigarettes, and cannabis and also crystal methamphetamine. We mustn't judge people and blame them for this. We need to understand "why?". We can use the opportunity to engage in a discussion, rather than saying, "Don't use. You're a bad person for using substances". Rather say: "Let's try to understand why you use it." Try to engage people in a discussion around that. A therapeutic discussion.

Physical health is very important, with Australians with schizophrenia dying 20 years younger than they should, often because of cardiovascular ill health. Smoking is the number one problem. Unfortunately we haven't made much progress in reduction of smoking among people who have schizophrenia. In not tackling these things we are doing people a disservice. There are other cardiovascular risks, including obesity, diabetes and hypercholesterolemia. One of the things we need to bear in mind as clinicians is to make sure that we advocate for our patients getting the best medications which are not making things worse for them in terms of their cardiovascular risks. I won't name particular medications but some cause metabolic problems. We need to choose our medications carefully. We need to be addressing the ongoing risks associated with medications very carefully, and we need to be ensuring that we are addressing the physical health of people with schizophrenia and related disorders.

So as a conclusion to what I've talked about thus far – and this is a thing very dear to my heart – people with schizophrenia mostly want to be part of society, they want to be engaged meaningfully in society.

I think the programs you people have in terms of the Association and the other non-government organizations represented here are transformative in the sense of getting people into work and keeping them in work. We do relatively badly in this in Australia and we should learn from you.

**Recovering from Schizophrenia**

There are many modalities that seem to work and may be just a little bit helpful for people with schizophrenia, at least some of the time. We have no magic bullet, no magic wand, but we know that a combination of these different processes and programs can be helpful if you get the combination right.

Suffice it to say that we do have effective medications and these are the foundation on which we need to build everything else. Part of the problem is assuring adherence. Consideration should be given to long acting injectables (LAIs) and we suggest they can be used early on in the treatment journey. And patients are much more accepting of them than clinicians, often. Psycho-education, about decision making and ideally how we engage a person in a discussion about medication is also key. The talk by Prof. Sally Chan about the use of web-based and other technologies that can be very helpful for us in terms of shared decision making was illuminating in this regard. I think Prof. Mike Slade will pick up on this in a later talk today.

Case management is central to effective management of people with schizophrenia. Case management works if it is done right. Part of it is case load. The talk yesterday about case loads of 60 or more, this is too high. You cannot do the real high fidelity case management with that sort of a case load. Along with that, resources. How do we do this? Partly with collaborations with other potential people, like non-government organizations.

Family is critically important. Again, we don't do very well in Australia with regard to family therapy for schizophrenia. One of the best predictors of a good outcome with schizophrenia is having good family support, and we need to ensure we include families meaningfully in longitudinal care.

We use some psychological treatments, including cognitive behaviour therapy. We are also very interested in acceptance commitment type therapy. And then things like social skills, and supportive work and cognitive remediation.

Holistic care encompasses things like exercise. It has been shown to be beneficial for schizophrenia not just in physical health terms but also in terms of psychiatric symptoms. One study from Peter Falkai showed that if you scan the brain of people with schizophrenia who exercise, the hippocampus shows some increase in size. I don't know if you think a lot about your hippocampus. Do you have desires to have a bigger hippocampus? Everybody wants a bigger hippocampus. How can you grow your hippocampus? You've got to nurture it, look after it. Don't drink too much alcohol. Meditation grows your hippocampus. Exercise grows your hippocampus as well. The point I'm trying to make is that looking after the whole body can actually help the whole mind.

Diet we are very interested in now. We've done a study called the SMILES Study, which was not with schizophrenia but with people with depression. We used a Mediterranean style of diet, basically getting a lot of olive oil. We found it was highly effective for mood. We now advocate it for people with schizophrenia as well because of these findings and also because it has a strong tradition of reducing cardio-vascular risk.

And then some things we've largely forgotten. Unfortunately in Australia we've moved to very fragmented services and we've lost of lot of things which I think are very important. One of the areas I have really liked is a study from China about horticulture, getting out and about with plants. A randomized trial showed people with schizophrenia who were engaged in horticulture three times a week, did really well, in terms of symptoms. Not what you might expect, but important.

Another thing which I like very much is music. We've had a lot of nice opportunities to dance and sing the last few days. The power of music should not be under-estimated. We've done a number of studies in this area and again we had very nice effects. Part of it is the social affiliation. One of the

best experiences of my clinical career in terms of severe negative symptoms of schizophrenia was one associated with music. I had a music teacher who developed schizophrenia in his late thirties, had then become very reclusive, and had lost contact with his family. Whenever he came into his sessions with me he was very demoralized, dishevelled, and didn't make eye contact. This was despite having been on clozapine. I eventually persuaded him to engage in a music group with a music therapist. The group got together with some ensemble work and actually worked together to produce a song which they ended up recording at the end of the music therapy program. He changed, much more than he ever changed with clozapine. He would come into the sessions well groomed; he made good eye contact; and felt that he had worth again. He felt so much that he had worth again that he made contact with his daughter. He had had the idea that his daughter didn't want anything to do with him because he was not worthy. In fact she had never thought that and she was delighted when he made contact with her again. So again, social contact. A marvellous thing, through music.

**Treatments that work**

I mentioned the idea of cognitive remediation. I think this is important. You can teach people cognitive skills. The problem is that you have to generalize, a bit like social skills training. The work I like most with cognitive remediation is the example from Susan McGurk and Kim Mueser in the US, particularly trumpeting the notion of linking mediation with work placement support. The idea is to look at the cognitive package and the things which you can teach in terms of building cognitive function around particular work requirements. That can increase your work placement ten-fold and can increase your income ten-fold; so we need to look at these packages and bring them into the mainstream.

I mention acceptance commitment therapy (ACT), a very nice dialogue partly about valued living. A trial in schizophrenia by Frances Shawyer and colleagues showed a reasonably large positive effect size for psychotic symptoms, but most importantly I think was the reduction in hallucinatory distress. Many people with schizophrenia, as I said earlier, have on-going symptoms hence reducing distress associated with these symptoms, can be very helpful.

There are new things we've heard about yesterday, such as app-based technologies. There is also nice work from Tom Craig and colleagues, building an avatar of the person 'behind' the voice that is heard as a hallucination. The avatar is projected onto a screen and a therapist behind the screen help the patient develop strategies to help with those hallucinatory experiences.

Transcranial Magnetic Stimulation (TMS). I haven't been very excited with TMS for schizophrenia. It can be very useful depression but not so much for schizophrenia, where the trials are very mixed partly because of lack of consistency around targets and so forth. But recently there was a paper which was very interesting. Nancy Andreassen, many years ago, championed the notion of cognitive dysmetria and cerebellar dysfunction among patients with schizophrenia. This recent study targeted the cerebellar connections with frontal lobe, with some benefits for negative symptoms. And remember Electroconvulsive Therapy (ECT) is still there as a treatment for some people who have failed other treatments.

What about the dopamine hypothesis? It's still our prevailing neurochemical hypothesis. We acknowledge it is very complex. It's not just about too much or too little dopamine. It's about the balance of dopamine in the brain, and psychopharmacology it is about getting that balance corrected, to ameliorate positive and negative symptoms. Cariprazine, which is not yet available in Australia but is approved in the US, targets negative symptoms and has particular affinity for the D3 receptor with a partial agonist effect. Cariprazine is a very interesting drug, and we'll see how it maps out in terms of clinical use. The point is that we have an array of different medications. The trick to my mind is to try to match the patient to the particular medication, using shared decision making; and then capitalize on the benefits which are afforded by the medications.

**Optimal Health Program (OHP)**

I'll leave you with those all of those thoughts and I'm going to share with you now a bit about

a program we developed, the Optimal Health Program. It's been going back about (I always feel so incredibly old saying this) 20 or 25 years, when we were confronted with the idea of what we could really do to bring together the optimal care of people with schizophrenia. It seemed to me the only way we could do it was to stop moaning about the system being at fault and really try and work with the individual. The individual is the only person who is there constantly, the still point in their turning world. So we set out a program of identifying needs, by talking to people, by talking to their families trying to build a program to empower them.

OHP is a comprehensive framework which involves consumers and carers and services. So everybody is involved meaningfully. There is a process of engagement not only of the person but also of the family members and of the services involved. In Australia the service structure is so complicated; I don't know how to negotiate the service structure, and goodness knows how anybody with a severe mental illness knows how to navigate such a complex structure.

Most importantly is the maintenance of ongoing health. We have a number of different tools we teach. A particular tool includes education, and that is knowledge about illness but also about wellness. Here the emphasis is upon doing the activities which you do best to keep yourself well. I think too many existing programs are too much about what happens when things go wrong and too little about when things go right. Why don't you just continue doing those things, right? But you've got to be realistic as sometimes things do go wrong, so we've got to build coping strategies into that and develop skills which can help. Underpinning it all is self-efficacy. I really like this notion.

OHP is delivered in a very flexible way. You can do it one to one, or you can do it group based; you can do it in one hour slots or you can do it in 15 minute slots. Different practitioners can do it at different times. So, if your case manager can only give 15 minutes over coffee to start the program, that's just fine. We developed OHP and we delivered it in two services, in a place called Canberra, a very curious city in Australia which happens to be the capital city. We were able to take two of the four catchment areas in Canberra and they employed OHP. The other two catchment areas carried on doing exactly what they were doing. The results were quite surprising. On the HoNOS, at baseline, the two groups were much the same. But over time the intervention group showed quite dramatic and certainly highly statistically significant reductions in scores; whereas in the control group the scores remained static. The Life Skills Profile (which is more about functioning) also showed improvements in the intervention group. We also managed to reduce emergency hospitalizations, as well as the amount of time in hospital. One thing went up and that was GP contact (primary care), but that was an outcome that we wanted. Instead of lining up at an emergency department or an in-patient service, you lined up asking help from your GP.

Figure 1 shows the OHP Session Outline. It seems very generic and in many ways it is; pulling together the strategies that seem to work together, in a meaningful way. We then introduce a tool called the 'I Can Do' model (Figure 2). We talked about medication and physical health, and Collaborative Partners. We look at Change Enhancement. We look at Visioning, Goal Setting. We look at Maintenance. And then you can put in as many Boosters as you like. That's another thing about the psychosocial treatments. People just tend to do it and then walk away. That's not the point. It's not how people use medication. Medication is on-going. Psychosocial therapies should also be on-going, so boosters are really important. So it's learning, then understanding in your own context, building strategies and all about building self-efficacy.

We mapped this all onto three health plans (Figure 3). I use a driving analogy. Mostly what we want to do is to be driving safely on the motorway in a nice way -- I know it's a bit tricky in Hong Kong with all the traffic, but nevertheless -- that's what we should aim to do. We're not driving all the time planning for an accident. We're driving all the time getting to our destination, right? So that's what Plan 1 is about, what you should be doing to maintain yourself. Plan 2 is about how to maintain yourself if things get a bit wobbly. For example, if there are road works, what do you do? Will you slow down? You make sure the tyres are pumped up, and so forth. You might take the car in for a service. Plan 3 is when you crash or break down.

| Session | Title | Content |
|---|---|---|
| 1 | **Optimal Health – Optimal Health Wheel** | Perceptions of health and behaviours that influence health |
| 2 | **The I Can Do model Part 1 - Strengths and Vulnerabilities** | Understanding the balance |
| 3 | **I Can Do model Part 2 - Strategies and Stressors** | Understanding and monitoring impact |
| 4 | **Medication** | Medication and Physical Health – Metabolic Monitoring |
| 5 | **Collaborative Partners & Strategies** | Identification of key partnerships – Connecting with key people |
| 6 | **Change Enhancement** | Understanding past events and defining change |
| 7 | **Visioning and Goal Setting** | Creative problem solving and planning – Developing, setting and celebrating goals |
| 8 | **Maintaining Well-being** | Health Plan 1, 2, 3 & Health Journal |
| Booster | **What is my health like now?** | Review health plans – Sign post achievement |

Figure 1: OHP Session Outline

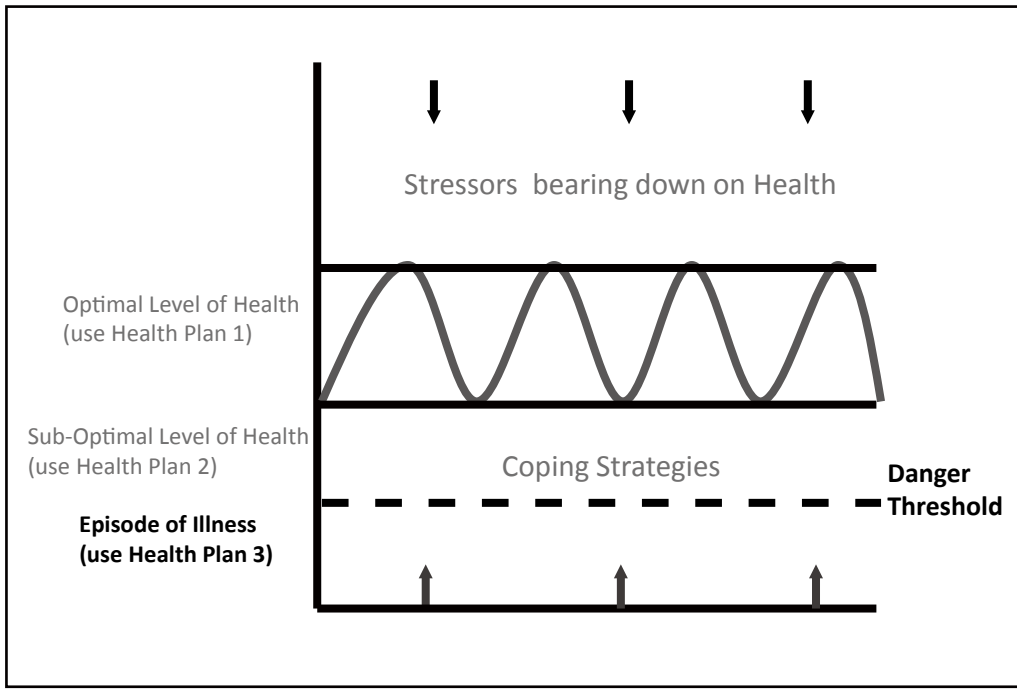


Figure 2: 'I Can Do' Model – Health Plans

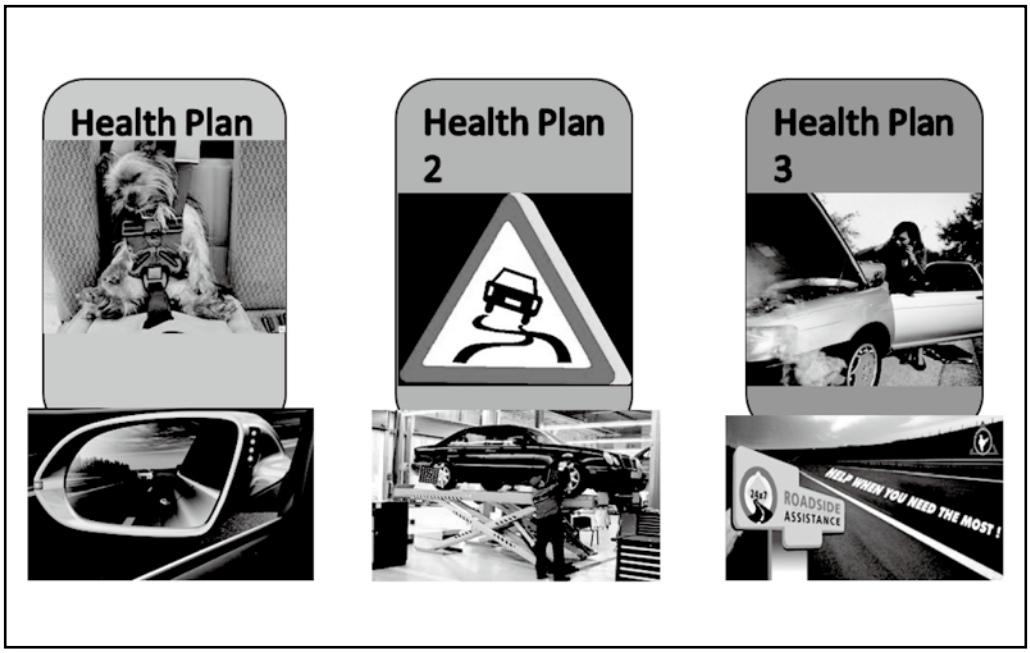


Figure 3: Health Plans

The model talks about stressors bearing down on health, and then what your coping strategies can be, and how they would be mapped onto the health plans. We are also very keen at looking at all the different aspects of people's lives and how this is a bit of a balancing act. It's not about symptoms as such but it's about all the different aspects of your life -- the strengths, the vulnerabilities and the balance. We map this onto a single Optimal Health Wheel (Figure 4), which we have now validated, and we can actually now populate that and look at how you are going in terms of different aspects of your life and functioning. We also have a Metabolic Monitoring system, so that part and parcel of OHP is looking after physical health. We also bring in Collaborative Partners. Involve everybody around you – your family members, your psychiatrist, your family dog. All of these people might be important for you and can assist you on your journey.

So continuing about this journey idea, it is important to have an understanding that when things go wrong, you can track back and understand it and look at what you might have done differently. Figure 6 shows how you can see how we can map this and how health plans would step in. Mostly you are keeping to your Health Plan 1, but that if things dip down, you can use Health Plan 2, and if that fails use Health Plan 3.

I am finished. Just to say that we have now developed this program for people with physical health problems, including adaptations for obesity, diabetes, kidney disease and stroke. We also have had collaborations with colleagues in the Region, including Malaysia, Indonesia and mainland China. I acknowledge the team, which is very large. Again, it is a great pleasure to have been able to talk with you today. Thank you.

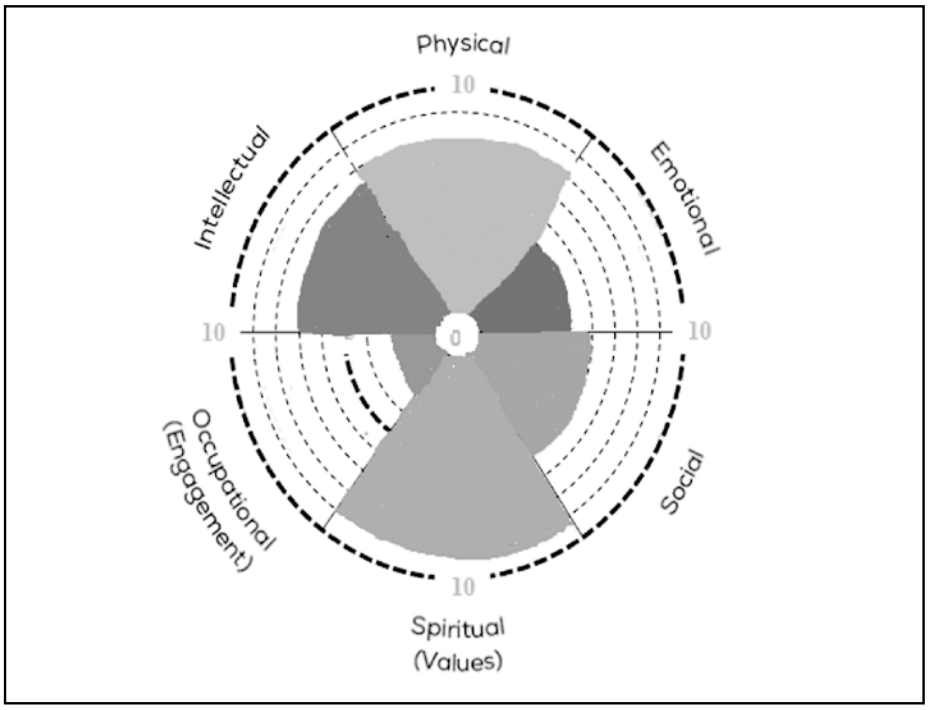


Figure 4: Optimal Health Wheel

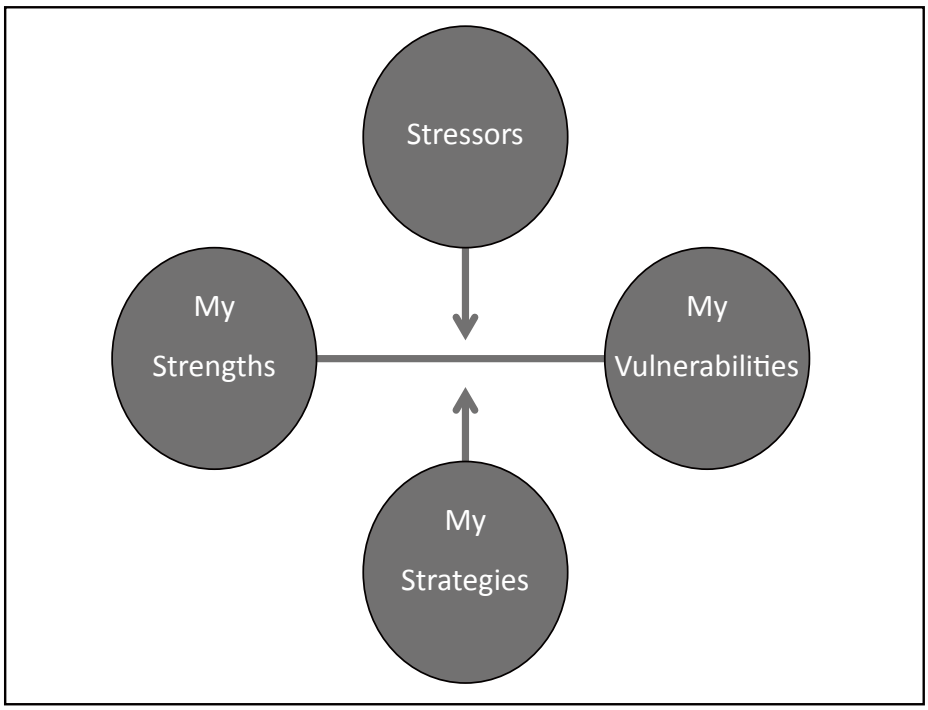


Figure 5: I Can Do Model

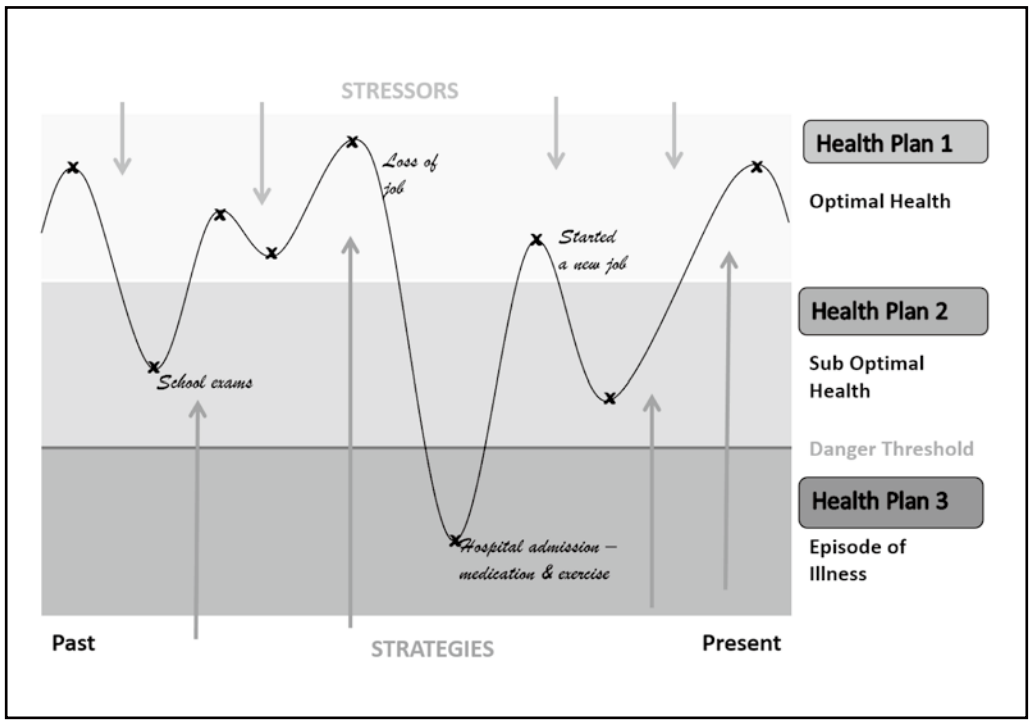


Figure 6: Understanding past events

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