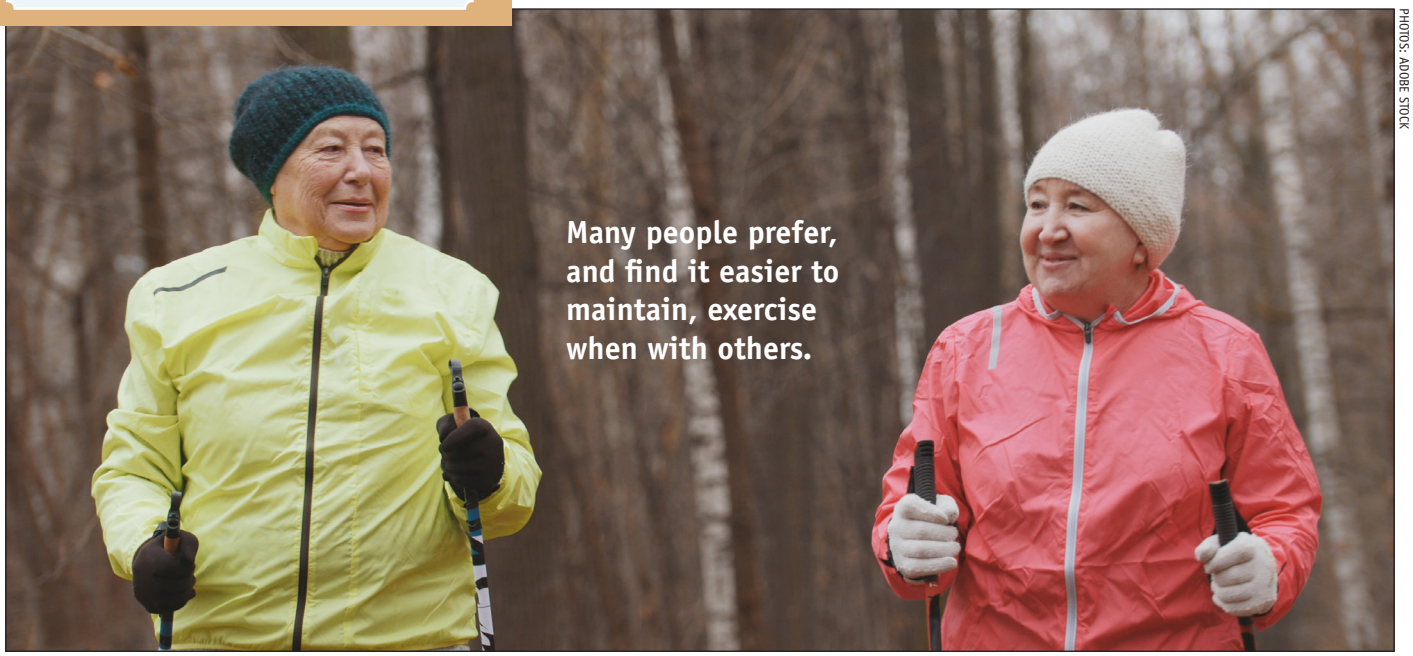

PHOTOS: ADOBE STOCK

Self-management of long-term conditions

Reasons given for positive and negative changes

In the third of a series of professional education articles based on the results of the *Talking about Health* study, the authors look at how participants were handling self-management of their long-term conditions.

By Melanie Taylor and Claire Budge

Introduction

Each year we asked the *Talking about Health* participants[1] about lifestyle/behaviour changes they had made to improve their health and wellbeing. Specifically, we asked whether the way in which they look after themselves (by monitoring symptoms, taking medication, doing "healthy" or "unhealthy" things) had changed during the previous year. The response options provided were: "no, it is the same"; "yes, I am better at looking after myself"; and "yes, I am not so good at looking after myself". A small number of people each year ticked both the positive and negative change boxes, as they were doing better in some respects and worse in others.

Those who indicated there had been a change – better or worse – were invited to explain how and why a change had occurred. The results are presented in Figure 1 (see p21). Figure 1 shows that most people indicated their self-care behaviour had stayed the same from year to year, and that this number increased slightly over time. Most of the changes that had been made were positive, but this number decreased slightly throughout the study period. Of the 297 people answering the question in all three years, 41 per cent said their behaviour had stayed the same each time, 49 per cent had made more positive than negative changes and 10 per cent had made more negative than positive changes.

What follows is a summary of the positive and negative change responses. The main themes are presented in bold type and quotes in italics.

Positive changes

Having a better understanding of conditions and accepting them and their associated limitations was described as being positive: *"I am getting to understand my health and what it involves more", "have come to terms better with managing what I can do and what I can't, though we are still trying to find the right medications to help with symptoms".* The advantage of greater knowledge was evident: *"knowing more about my condition helps me adjust to the new lifestyle I now have".* For some people, this resulted in them **being kinder to themselves,** eg *"becoming selfish looking after myself instead of everyone else".*

Associated with this was **improved self-awareness,** which related to knowing your own limits and **doing less,** or pacing activities by *"taking more time to do things", "I try not to overdo things because I usually pay if I do", "when preparing/doing jobs around the home I take breaks or sit and do things more so I'm not standing all the time",* and

protecting yourself: *"I am trying not to take on others' dramas, I don't need the extra stress"* and *"I am more actively aware of how I am feeling and take action accordingly"*.

Many observations related to **diet**. Better eating habits included becoming vegan, cutting back on alcohol, watching amounts eaten, taking health supplements and eating less fat and sugar. One person said they recorded their daily meals. Education had evidently played a part: *"after seeing the dietitian, I follow healthier eating habits and read labels when food shopping to avoid overloading with sugar, salt etc","I am aware caution is needed with food intake, try to adhere to doctor's advice"* and *"LTC nurse has given me really good advice"*.

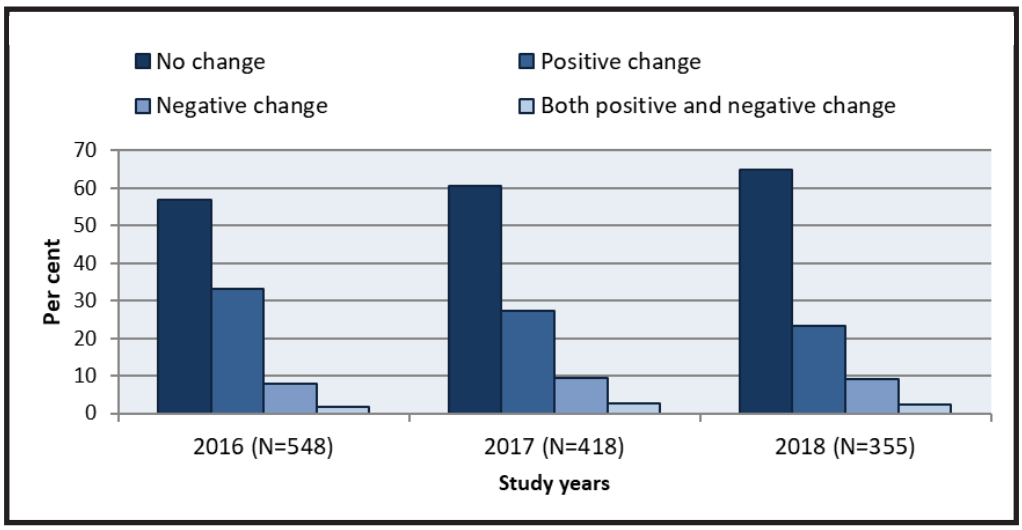

Figure 1: Percentage of people indicating they had made no change, a positive change or a negative change in the way they looked after themselves during the previous year.

Following advice and getting self-management support from a range of practitioners was mentioned positively: *"a lot has changed and I have the chemist. We meet every six weeks to discuss any changes and I also see the nurse on a regular basis to keep up to date"*. Practitioners included nurses, dietitians, pharmacists, mental health team, alcohol and drug services and doctors. Attending classes and using counselling services also featured, for example, *"I attend a regular counselling session to manage anxiety"* and *"I'm taking part in personal awareness/mentoring to review where I am in my life"*.

Exercise featured prominently, with people describing doing more structured exercise or building exercise into daily activities, such as walking children to school, or increasing time spent on housework and gardening. Referrals to physiotherapy, green prescription, U-Kinetics (a clinical exercise physiology programme now called OraKinetics) and personal trainers were also mentioned.

Personal growth in self-management was evident in some comments, for example, *"I'm not afraid to ask if I don't understand"* and *"I got help and medication for depression and with counselling started to see ways to gain control of my diabetes and weight"*. One person now sets their own exercise goals and records their progress in a log book.

Medication was mentioned frequently, with better adherence, medication changes and use of blister packs to aid memory being described. *"Better with the blister packs, medication is all organised for me"*. Better pain management due to a change in drug or regime was also mentioned.

Some people had experienced a **wake-up call** which had brought home to them the severity of their condition: *"the shock of blood glucose hitting 30.4 woke me up"*; or made them think about life: *"I had a heart attack, this changes one's thinking. It is very confronting"*.

Positive changes do not always work alone. There was ample evidence of improvement in one aspect of life positively affecting another. For example, feeling better mentally was associated with positive behaviour change: *"better state of mind, more exercise and greater/healthier food awareness"* and *"I've undertaken 4-5*

Those who were doing better . . .

A comparison between the positive and negative change groups in 2018 found no apparent differences in sex, ethnicity, age, living situation or ratings of support from the general practice team. However, those who were doing better:

- Were more likely to have had input from a specialist nurse or LTC nurse (51.4 per cent cf 44.8 per cent).
- Had fewer of the more commonly experienced LTCs (M=2.8 cf 3.6).
- Had notably higher income adequacy (54.1 per cent cf 25.0 per cent had enough or more than enough income to meet daily needs).
- Were more likely to have health goals (75.8 per cent cf 63.0 per cent) and say that a health practitioner checked up on how they were doing with their goals.
- Were *less* likely to have a care plan (14.3 per cent cf 25.0 per cent).

gym sessions a week, walk daily and am eating much more healthily than ever before. I've lost quite a lot of weight and become much more fit. This has helped my feelings of depression".

Negative changes

The **importance of exercise** was highlighted in many comments, where people acknowledged that not being able to exercise was having a negative impact on their overall wellbeing. *"I was more disabled so gave up gym and cardio then had weight and diet problems. Less exercise means more weight, 14kg plus – less motivation and willpower, less sleep, disillusionment and depression". "I've had to cut back on my exercise which has been very difficult for me. I used to go to the gym every morning but haven't been able to due to fatigue and stiffness in the morning".*

In some cases, a **specific incident** triggered a negative cycle: *"I had a fall. My exercise program could not continue. Increased pain and disability. Now I need two knee replacements"* and *"have torn a calf muscle and have had a back injury which has caused a lot of pain and stopped physical activity".*

A **lack of finances** was also held responsible for poorer management by several people. One said they found the cold in winter demotivating but couldn't afford to turn the heater on; another had worsening symptoms but had postponed going to the doctor due to cost. Others could no longer afford a gym subscription and were finding exercising differently too difficult to establish. Income influenced food choices as well, one person saying: *"I'm finding it hard to budget for good food – it takes planning and I haven't been diligent about it".*

Symptom exacerbation – pain, tiredness, poor sleep and breathing were mentioned – was responsible for a number of people looking after themselves less well.

General deterioration with ageing also featured: *"Need more assistance from partner with medications as I find my eyesight is fading a bit and I am not so switched on about times and doses", "movement is a bit more difficult as life goes on, breathless, need a bit more help".*

Lack of motivation was a common theme, people saying they found it hard to get out and do things, or had lost motivation due to something changing. *"I have a problem with motivating myself to do planned exercise. Sometimes this is because of the weather, sometimes I am just too tired to be bothered, or I am physically uncomfortable. I do try my best!"* A person with diabetes felt disillusioned by the demands of the condition: *"I've gained weight and know my blood sugars have been high at times. I've increased my insulin which I feel makes it difficult to lose weight. I get down and frustrated when I know my levels are high. Have felt discouraged that no matter what I do, it feels like it doesn't make a difference".*

The **role of others in motivating people** to remain active was evident in some comments: *"I have stopped going to the gym and not so many visits to the nurse. They were motivating me to diet and exercise". "I need to programme myself for exercise. When I was on a regular programme to go to health clinic for exercise I attended twice a week. Since the free sessions have finished I haven't continued with the exercises as much as I could have at home."*

More serious **depression** was mentioned by several people: *"my depression has got worse and sometimes it is a struggle to leave the house"* and *"due to my depression, sleep apnoea and insomnia I tend to shut myself off from everyone when I am home. Do not sleep at right times therefore do not eat at appropriate times. Tend to sleep a lot during the day".*

The **role of caregiver** took its toll on many people, as other people's needs took priority. Examples included: *"my husband has been very ill over the last 18 months and sometimes that overrides myself"*, and *"I am carer for my husband who is terminally ill and tend to put my own needs last. Therefore I tend to suffer slightly from not looking after myself better. I understand my needs but the time to exercise does not always fit in with the regime".*

The **loss of a loved one** through death or divorce increased stress, loneliness and social isolation. This resulted in problems with motivation to exercise and eat well: *"Marriage break up, just not coping"* and *"My husband passed away this year and for the last 6 months I haven't looked after myself".* One person said it had taken two years for him to get back on track after the death of his wife, for whom he had been the main carer for many years. As he said, *"perhaps sadness and loneliness should be classed as an illness?"*

Memory problems created issues for a few people, specifically in relation to medication: *"I find I am forgetting to take my insulin at meal times, then when I do a blood test the reading is really high", "Sometimes I forget taking my medication or inject insulin".*

Earlier we noted that sets of positive changes in self-care behaviour appeared to be inter-related, and the same was true of negative changes. A downward spiral was apparent in several of the descriptions: *"Because of breathing problems I no longer walk 40 minutes*

Practice points

- Ask about people's self-care challenges, eg pain or sleeping problems, and get them to share with you *how* they affect their mental/physical health or lifestyle. You may find a single problem has developed into multiple problems, but there may be a way of addressing at least some of them and stopping a negative consequence spiral.
- Many people prefer, and find it easier to maintain, exercise when with others. A gym membership, green prescription or class enrolment might help, as might encouragement to find a friend to walk with. You could phone them to check how they are doing in sticking to an exercise plan and brainstorm some different ideas if things are not going well.
- Consider options for people who can only exercise a little, or who need to improve their strength and balance. Seated exercise (such as a pedal exerciser available from mobility stores), in-home programmes, or the 9am Saturday morning show on TV One, *Healthy for Life*, hosted by Bernice Mene, may be suitable.
- When making suggestions about healthy living, consider how much income people might have to put goals into practice. Find out what programmes or group activities are available free or cheaply in the community to encourage people to exercise. Remember to accommodate people's own preferences based on their personal lifestyle.
- Be aware of the difficulties people face when caring for whânau and how it might affect their own health. Encourage them to make some time for themselves and learn how to ask for help from family members/neighbours when they need it. For example, they could ask a neighbour to come and have a cup of tea with their spouse while they have a walk. Many people are happy to help out if they know what is wanted.
- Although the caring role is one many people adopt willingly, and it has its rewards, it can also be demanding, limiting and emotionally difficult as a loved one deteriorates and loses independence. There can also be feelings of guilt about having negative thoughts about the role, or feeling that you are not coping or doing enough, which adds to the burden. Encourage people to talk about how caregiving makes them feel, and support them in finding ways of dealing with frustration, irritability or sadness. They may need practical help or respite care, but not know what they are entitled to.
- Provide help with meal planning by referring people to the Health Navigator page "Budgeting and healthy eating" (www.healthnavigator.org.nz/healthy-living/b/budgeting-and-healthy-eating) to enable people to eat healthily without blowing the budget. Suggest some ideas for planning ahead for bad days when energy levels might be down, eg cooking a larger amount and freezing a portion or two for another day, or having some healthy snacks on hand for times when appetites might be poor. We know from other parts of the study that some people struggle with reading and understanding nutritional information on food labels, so helping with this might be useful too.

Be aware of the difficulties people face when caring for whânau and how it might affect their own health. Encourage them to make some time for themselves and learn how to ask for help.

- Health Navigator also has some great consumer videos to support people on lifestyle or behaviour change (www.healthnavigator.org.nz/videos/b/behaviour-change/).
- Practitioners need to remember that change is not easy and that, for many, conversations to help them become more ready, willing or able are a necessary component of effective self-management support.
- People may benefit from attending The Chronic Disease Self-Management Programme (often called the Stanford Programme) available in most parts of New Zealand. This six-week self-management programme covers healthy eating, exercise and the symptom cycle, among other things. Some regions run programmes targeting specific conditions, such as diabetes or chronic pain.
- The importance/confidence ruler is a good way to help patients fine tune goals. See www.smstoolkit.nz/goal-setting-and-action-planning on how to use these tools. A high score on both rulers suggests the person is more likely to be successful with behaviour change.
- Life changes, such as death, serious illness in the family or divorce, can have a major impact on people's self-management behaviour. Extra self-management support at this time may help people maintain healthy lifestyles.

every day. This has caused more problems for me – less socialisation, depression etc" and *"I find I get out of breath just walking to the shower so don't shower regularly. I don't eat properly because of pain and breathing, no exercise."*

Positive and negative changes

A few people described both positive and negative changes, and that probably reflects reality for many more people. One person wrote in the positive box, *"I try to follow healthy eating, but sometimes go off the rails and have sweet thing or chippies as get craving for them and also carbs. Also make sure I have my veges, fruit, go for walks with my pup"* and in the negative box, *"when feeling tired or in pain, things are let go eg do not cook dinner or sometimes miss meals and exercise as well".*

Discussion

Most people said the way they had looked after themselves during the previous year had stayed the same, but the descriptions provided by those who indicated it had changed shed some light on how people define good self-care. Examples included exercise, diet, medication, independence, use of mobility aids and putting themselves first. What patients and practitioners define as good self-care may differ. One study found that people with diabetes defined self-management in relation to diet, non-medical approaches and managing symptoms of comorbidities, whereas practitioners focused on medication and were frustrated by their inability to influence patients' self-management.[2]

Despite 29 per cent of participants saying they had no health goals,[3] many described ways in which they were doing better or worse, suggesting they did have some sense of what they were working towards or trying to maintain. What represents "looking after yourself" clearly differs depending on who you are and what you want to achieve. For example, increased exercise was a positive achievement for some, whereas for others learning to do less, or to approach tasks more gently represented a positive change.

Overall, it appears that when things had changed for the better, it was framed as the individual putting more effort in, eg following advice, doing more exercise, cooking and eating more healthily or taking medications more regularly. However, negative changes were often a result of something out of the individual's control, like general ageing and concomitant deterioration, exacerbation of symptoms or an event such as a fall or emotional loss. The negative impact of caregiving responsibilities should also be noted.

The self-care behaviours we identified were similar to those found in a study of barriers to self-care for people with long-term conditions. These included physical limitations, lack of knowledge, financial constraints, need for social/emotional support and medication concerns. The authors concluded that many of the identified barriers stemmed from self-care being more complex in the context of comorbidity.[4]

This appeared to be so for our participants, a change in one condition triggering a change in another. Also evident in both the positive and negative comments was the complexity of the interplay between symptoms and reactions. Having a symptom such as breathing get out of control can lead to decreased activity and more pain. Conversely, an improvement in mood or more effective pain relief can result in increased activity and more investment in eating well. Consequently, it is worth putting effort into supporting people even if they are only able to work on one aspect of their lives, as it may have a ripple effect on other aspects. •

Key points

- PARTICIPANTS described a broad range of self-care behaviours which represented how they were looking after themselves better. These differed from person to person.
- BEHAVIOURS included: developing better understanding of self, conditions and associated limitations; increased exercise; better diet; attending classes/education; weight loss; having counselling; accepting help; using mobility aids; maintaining independence and knowing when to stop doing things.
- THE ways negative changes to self-care, such as less exercise or a less healthy diet, were described often suggested there was a specific trigger – limited finances, a specific event/experience, exacerbation of existing symptoms or general deterioration due to disease progression or ageing.
- THE role of caring for others and putting others' needs first was also seen as having a negative impact on people's ability to look after themselves.

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References
1) Taylor, M., & Budge, C. (2020). Talking about Health: Study overview and self-care challenges experienced by people with long-term conditions. *Kai Tiaki Nursing New Zealand, 26*(2), 20-23.
2) Cramer, H., Rooshenas, L., Robinson, B., & Baxter, H. (2016). 'The main bug bear is that patients don't real want to change': Patients', health professionals' and health service commissioners' perspectives on self-managing diabetes. Retrieved from https://nomadit.co.uk/conference/easa2016/paper/30459
3) Taylor, M., Budge, C., Hansen, C., Mar, M., & Fai, F. (2019). Written care plans and support for health goals: Important components of long term conditions care. *Kai Tiaki Nursing Research, 10*(1), 29-38.
4) Bayliss, E. A., Steiner, J. F., Fernald, D. H., Crane, L. A., & Main, D. S. (2003). Descriptions of barriers to self-care by persons with comorbid chronic diseases. *Annals of Family Medicine, 1*(1), 15-21.