## WE NEED TO HELP PATIENTS TO HELP THEMSELVES

## Neil Piller

Performing the same task day after day, week after week is not only predictably routine, there is also a danger that we may avoid doing it altogether. Perhaps worse, fear of losing face may result in us telling people we have been performing the task when, in fact, we haven't.

Imagine you're a therapist treating a patient, let's call her Susan, and expecting her to self-manage her lymphoedema. However, at follow-up visits you continue to see poor outcomes, despite assurances from her that she is carrying out the treatment at home. You might mistakenly change Susan's treatment in the belief that what you have recommended is not working when, in actual fact, she has been neglecting to do as you asked.

Other than the patient themselves, treatment fatigue can spring from all kinds of sources — for example, financial fatigue (limited funds for optimal treatment), travel fatigue (time spent getting to and from therapy appointments), or insurance fatigue (where companies will only support a limited number of treatments per year) can all play a part.

So, as therapists, how do we overcome the problem of maintaining patient interest in routine procedures? It's not easy, but educating healthcare providers about the benefits of early detection and targeted treatment will help, as will making treatment more readily available in rural and remote areas, thereby reducing a patient's need to travel.

However, as therapists our greatest leverage point is with patients themselves, specifically in terms of the relationships we develop, the often frank

Professor Neil Piller, Director Lymphoedema Research Unit, Department of Surgery, School of Medicine, Flinders University, Adelaide, South Australia communication we need to have with them and the openness and honesty that hopefully follows.

So how do therapists make things better? For a start, we all need to listen a little harder and ask more open questions — 'why!', 'how?' and 'when?'

Then there are procedures that evidence tells us work, including early detection (using bioimpedance spectroscopy and tonometry, for example), early intervention and treatment, and patient-centred management.

In the early stages of lymphoedema therapists are usually dealing with accumulated fluids (lymph), rather than

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significant structural cellular and tissue changes. However, just because the swelling seems to relate to a recent event, such as treatment for cancer, does not mean that being aware of the patient's associated medical history (such as hypertension, thyroid and kidney issues) or medication should be neglected. After all, familiarity with patients' histories and comorbidities allows us to monitor their effect on already compromised lymphatic systems.

Equally important is the therapist's knowledge about the patient themselves — their family history, whether they have access to carers, living circumstances and even their social networks.

A perfect example that comes up often in practice is the compression stocking. There is little point in fitting the ideal pressure stocking for lymphoedema control if the patient lives alone and cannot apply it or take it off. The result will be reduced compliance

and lowered treatment impact.

Similarly, patients may have a dedicated carer or partner, yet their impact will be negated if they are never instructed in how to help effectively. The patient's compliance might be OK, but the treatment itself will be sub-optimal.

Further understanding the needs of patients is also critical and it is important that therapists ask what they are looking for. Perhaps they are expecting a reduction in limb size, or maybe they want an improvement in how their limbs feel or the range of movement.

As therapists, we must become accustomed to understanding what a patient's decisions mean in terms of outcomes when matched against our relatively poor expectations of best practice. However, if we expect patients to be reasonably compliant, we also have to respect their treatment wishes.

We can all become complacent and lose enthusiasm, especially without feedback, so this too is an important part of the interrelationship. For instance, we might feel its OK if a patient's limited movement means putting the limb into a 'holding pattem', where it neither worsens or improves. However, it is still the therapist's duty to remind him or her that neglecting to care for the skin will compromise its barrier function. This kind of feedback is simply part of the highs and lows of treatment.

Whatever treatment plan patients and therapists choose, behind it all there must be, from both sides, an intent, an understanding of outcomes and a willingness to be proactive. This involves acknowledging the input of all involved and celebrating great outcomes, while still accepting that some targets are beyond the limitations of the patient. Following these principles might just help us all to help better:

For a patient perspective see Liz Dart's piece on p8.