

# Coping with Breathlessness

A Talk by Emma Dix & Sara Heritage, Occupational Therapists NNUH

Occupational therapists are trained to support people with health problems to adapt and find practical solutions to help manage the daily activities that are important to them. Emma and Sara did not talk about pulmonary fibrosis particularly, more the challenges for both patients and carers of living with a condition that impacts so much on daily life.

They talked about conserving energy so that you can manage the activities you really want to do. It can help to visualise a certain amount of energy available each day – like a jug of water or a battery – each activity drops the level a little and if you don't rest at times to allow the energy level to top up again, you risk running out before the end of the day.



They suggested thinking of the 'four Ps':

- **Prioritisation** – think about the things that are most important for you to achieve that day and make those your priority. If something is not that important, can it wait until another day, could you ask someone else to do it for you? People often want to help – let them know which things are too much of a struggle, they will usually be glad to have a definite job to do.
- **Planning** – this is about thinking ahead. Do you find first thing in the morning difficult or is later in the day more challenging? Can you reorganise your day? If mornings are your worst time, can you shower or bath in the evening? Can you avoid arranging activities for the times you know you tend to feel most tired? Try to alternate heavy and light tasks. Plan activities throughout the week and share that plan with friends and family so that extra things don't get added that you can't cope with. Try to plan for rests and ensure you get the best rest you can at night. Working out what you need to get done and planning realistic goals can make things more manageable – make lists if that helps.
- **Pacing** – try to break activity into manageable chunks, take your time and allow for recovery to 'top-up the battery' again. Stairs can seem like a mountain, but breaking it into 2 or 3 stages, with a pause after a few steps to catch your breath, can mean that you are less exhausted at the top. **Listen to your body** and know your limits – **rest before you are tired!**
- **Positioning** – sitting reduces energy use considerably; can you sit to do things you may have previously done standing (washing up, peeling veg, potting seeds...), would it help to use a trolley to move things around rather than carrying things, can you raise beds in the garden to save you bending? Try putting extra seats at strategic points so that you can rest if you need to. Is there any other equipment that might enable you to conserve some energy? If the stairs are exhausting, would a stairlift help? Energy conservation can help you to feel more in control, more positive and less frustrated by the limitations of your illness. Focus on the things you **can** do rather than the things you can't. Maybe think about taking on some tasks that haven't traditionally been your role in the past – perhaps you could help with light household tasks or try a new hobby? If you can be realistic about what you can achieve, you are more likely to feel more motivated and more satisfied with your day.

Communication is important too – it can be very difficult for carers and families to know how much to let you do because they don't want to see you get too puffed. Let them know what they can do to help, and what it is you need from them. It may be that you feel you can manage and cope with getting a bit out of breath, provided you are given time to get your breath back before you have to speak. Do you need them to just be there for reassurance when you are puffed? Or open a window or pass your fan? Perhaps you need a drink to

help with a coughing spell. Or maybe you just need to be left in peace for a few minutes? It might be different on good and bad days so plan for that too. It is much more manageable if you all know what to expect.

**Carers** need help and support too. Living with illness is not something we really expect and can add a lot of stress to relationships. Talking about how you both feel can make it easier to understand what it is like for the other person too. Sometimes it helps to talk to someone else – a friend, family member or a health professional or voluntary organisation if you need to speak to someone who is not so close to you. The energy stores of those of you who are carers are not endless either and it is important you look after yourselves too. Ensure you get enough rest, eat well and are able to take a break if you need to. It is important to plan for the unexpected – if a carer also becomes unwell, even if it is the sort of illness we can normally cope with easily like a cold or a tummy bug, doing the extra tasks when you are the main person looking after someone can feel too much. Make sure your GP knows that you are a carer – surgeries keep a register of carers who may have additional needs for support. Allow others to help too – perhaps have a list of people you can call on, someone that can do a bit of shopping for you or run an errand or someone who can come and spend an hour or two, whilst you go out for a bit or have a rest.

Support groups can be helpful for carers as well as people diagnosed with a long-term condition – you are very likely to meet others who are in a similar position to you and it can help to chat to someone who really does understand what living with a lung condition is like. You can't make the problems go away but if you can just share your frustrations and worries that can make a difference. Practical support is available from Social Services or from services like the SWIFTS service which provide a 24-hour phone contact and can provide care in an emergency, for example if someone has had a fall but doesn't need to go to hospital or if a carer is unwell. Charities like the Red Cross and Age UK can help with advice and some practical aspects – equipment loan, benefits advice etc. as well as the more specific advice from the lung charity helplines. If you are struggling with stress, anxiety or feeling low, the Wellbeing service can help. You can refer yourself and help is available over the phone, on a 1 to 1 basis or in groups.

Finally, finding time for relaxation is important – it can relieve tension and anxiety, help with managing panicky feelings, conserve energy and reduce fatigue. Sara talked us through a simple **relaxation technique** to reduce muscle stress and calm the breathing (and during the 15 mins or so of the exercise, even in the less than ideal surroundings of the Willow Centre, not one person coughed!).

- Sit or lay somewhere you can be comfortable & not interrupted.
- Close your eyes or focus on something in the distance.
- Start by scrunching up your toes for a few seconds, then release, notice the difference between the sensations.
- Keeping your breathing steady, tense and release each muscle in turn, working your way up your legs, thighs, buttocks, stomach all the way to your shoulders, face and hands.
- Repeat if you still feel tense, then relax for a few minutes before slowly and gently beginning to move again.

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