



Introduction

Loss of energy and strength are very common problems in people living with a life limiting illness, and can be the source of considerable distress and frustration to the person who can no longer do all the things that they used to be able to do. Unfortunately, while many of the other symptoms that arise with a life limiting disease can be relieved, there is little if any relief from feeling low in energy and weak in the body.

Energy levels and strength can be affected by one or more reversible factors including pain, nausea and vomiting, constipation or diarrhoea, anaemia, depression, and the effects of some medications and treatments (such as radiotherapy and chemotherapy). To some degree, these problems can be overcome. However, 'anaemia' (a low blood count) can often be a contributing factor to weakness in an advanced life limiting illness and transfusions cannot always be relied on to reverse this. You will need to talk to the doctor in your care team about the merits of this option if the person you are caring for is known to have a low blood count.

It is important to understand that low energy levels and weakness are not driven by the choice or attitude of the person with the life limiting illness, but by the illness itself. Tumours caused by cancer can trigger the over-production of certain naturally occurring chemicals which then flood the body and bring about metabolic changes that result in a syndrome of a near complete loss of appetite, significant reductions in energy levels, muscle strength, stamina and an irreversible weight loss.

Although this syndrome is well understood, there is to date, little that can be done to overcome it. Encouraging people in these circumstances to eat and drink more is not particularly helpful as it will not result in an increase in body weight, nor does it translate into an increased amount of energy and muscle strength. Often such efforts become the source of stress and frustration both for the person themselves and for those who are caring for them.

Regular short periods of gentle exercise may be of some assistance to some people. For others the effort of exercising is burdensome and of no value, especially if it involves directing what little energy they have away from doing the things that give them most pleasure. Often such efforts become a source of stress and frustration in themselves.

How to care for someone with low energy level and weakness

The twin challenges for a carer of someone who is weak and low on energy relate to coping with frustration and supporting the person as they adapt to new limitations.

Not being able to do what they want to do because of weakness and loss of strength can be very frustrating. Letting go of a range of favourite activities and setting aside important jobs that need to be finished can represent a whole series of losses which can bring with them a range of feelings including frustration, sadness, anger and resentment. For some people, no longer being able to do the things that gave their life meaning brings on feelings of grief and despair. This is particularly the case when a person is no longer able to independently perform the day-to-day activities of self care and personal hygiene. Loss of independence in this area can be frustrating and can contribute to a feeling of loss of dignity and worth. It is important to find opportunities to talk to the person you are caring for about the need to let go of some tasks and your willingness to take on these tasks for them. The members of your care team can support both of you as these adjustments are made.



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Organising and managing the day

When energy levels are low, it is important to use what energy is available on the things that bring the most rewards and fulfilment. For example, if having a shower each day robs a person of all their energy for the rest of the day, it may be that showering less often is a means of saving energy for more important things. Equally, a home nurse may be able to help with this task so that the person being cared for can spend their energy on more pleasurable activities. Let them decide what things they want to do with their limited energy reserves.

Assessment and input from a physiotherapist and occupational therapist may be beneficial in adapting activities and in the provision of appropriate aides or adaptations to equipment for use in the home.

A little planned exercise can actually improve quality of life for some people. Depending on the level of available strength, you may gently encourage some kind of physical activity each day. If you are caring for someone who cannot get out of bed, ask the nurse or physiotherapist in your care team about gentle passive limb exercises. If the person is mobile, aim for some pleasant form of daily activity such as a walk to the shop or to the letterbox or sitting out of bed for meals.

Pain control is important, as poorly controlled pain can make exercise and activity difficult or burdensome, and can quickly contribute to exhaustion and lead to frustration and despair.

Encourage adequate rest, both in the form of daytime naps and a good sleep at night. Seek advice from the nurse or doctor in your care team to help overcome any sleep problems.

Alternate periods of activity and rest during the day, vary the activities of the day, and try activity just before meals and rest after them.

Progressive loss of energy and strength are part of the natural 'winding down' process that occurs at the end of life. Discuss the concerns you may have about this with the nurse or doctor in your care team. In certain circumstances there are medications that can be used to stimulate energy levels, but the results are variable and cannot be relied on indefinitely to reverse the problem. Again, discuss this with the nurse or doctor in your care team.

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This information should be read in conjunction with the advice provided by your palliative care team.