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Information for patients Coping With Bed Rest



Midland Centre for Spinal Injuries



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Coping with Bed Rest

Following a spinal cord injury it is not unusual for patients to need to spend a period of time lying flat in bed. This is often the case immediately following the injury, to allow optimum recovery. In addition some people require bed rest at other times as a result of skin problems and lying in bed enables them to keep pressure off vulnerable areas. Being on bed rest can be very restrictive and many people find it difficult to cope. This booklet provides information about being on bed rest and includes some ideas about ways of managing this time.

Why is it necessary to stay in bed?

Obviously, every individual is different, so it is important to talk with your own medical team about what is the most appropriate way of managing your injury. Feel free to ask questions as it is important that you understand the plan for your treatment and are in agreement with this.

Bed rest may be necessary for a variety of reasons.

- If there is a fracture of the spinal bones, bed rest can be undertaken to allow healing to the fracture ('Conservative management of spinal fracture'). Lying still in bed can enable bones in the spine to start to heal and fuse together, in the same way that a broken bone in the arm or leg would heal when it is kept still by applying a plaster cast. In contrast, rather than allowing bones to repair naturally sometimes it is decided more helpful to do surgery to fix bones together. If you have had surgery to stabilise your spine, then you may require less time lying flat on bed rest, than someone who has not had surgery.
- Bed rest is also thought to be helpful to promote recovery within the spinal cord itself, which runs within the spinal bones. The spinal cord is the main nerve trunk that runs within the spinal bones. The spinal cord carries messages from various parts of the body to the brain and then takes the brain's instructions to various parts of the body. It lies within the spinal bony column.

Summary

- Many people find bed rest very difficult to cope with. It is important that you understand the reasons for staying on bed rest in order to help you through this time.
- Do not be afraid to let the staff know what you need, as this will enable them to support you in the most helpful way.
- Look after yourself and help your body to recover as much as possible. You can do this by resting, eating and drinking regularly and following advice from your medical team.
- Try to keep yourself occupied, using some of the suggestions described in this booklet.
- If you are experiencing difficult emotions and feeling worried, talk to someone about this and try to do what you can to reduce your concerns. Once you have done everything you can, try to distract yourself from worrying and focus on what you can do in the days and weeks ahead.
- Whilst we appreciate that this is a hugely difficult and worrying time, you do need to stay in bed and allow your body to recover. If you can accept this, you can then try to find ways to make the most of the time.
- You are not going through this alone and we are here to help, we consider our patient and their families to be part of our family. However if you don't tell us, we can't change or do anything that may be upsetting you.

How to deal with worrying thoughts

Try to look at the worrying thought more objectively. What is it that concerns you most? Is there anything that can be done about this? Would it help to have more information? Could anyone else help or do something to make this easier? Would it help to talk this over with someone? If you think there is something that could be done, then take action! Do what you can to resolve or minimise the problem.

Once you have done everything that you can, is it possible to put the worry aside for now, as further worrying will not be helpful. Some people find it can help to write a list of worries, so they can literally put them aside until a later time and they won't be completely forgotten. There is a Guatemalan tradition to use 'Worry Dolls' in a similar way.

You may find it helpful to have activities you can do to distract yourself at times of worry. It may help to make a phone-call and have someone to talk to, to put the TV on, or, to do a puzzle or other activity that you can focus on. Often worries come when we are on our own and there is little distraction. For this reason night time can be when lots of people feel most distressed or worried. Do talk to the nursing staff if this is the case, the staff will be awake and busy throughout the night, so should be available to reassure you or set you up with something to do.

Some people find it helpful to use Relaxation Strategies, to help them to switch off from worries. This can include breathing exercises, focusing on relaxing the body and visualising different calming and pleasant scenarios. If this is something you would like to try the Psychology Team will be happy to practice different relaxation exercises with you.

Many people find it helpful to be able to go to a safe place or happy time, in their thoughts, when they are finding things difficult. Whilst you are physically unable to leave the situation you are in, if you can mentally take yourself away for a while this may help you to cope. People often think about holidays, places they have been or would wish to go or doing an activity you enjoy. Close your eyes and imagine what you can see, hear, feel and smell around you. The more senses you can involve the more vivid the experience. Being able to do this may help you to get through a difficult time or distract you from worrying thoughts.

If the spinal cord has been damaged, lying flat provides the optimal conditions to prevent any further damage to the spinal cord. It also allows for any natural recovery of the damaged nerves. Soon after a spinal cord injury the damaged nerves within the spinal cord can go into a state of 'shock'. There is also bruising and swelling of the spinal cord.

At the Midland Centre for Spinal Injuries we believe that it is best to allow the bruising and swelling to settle down prior to getting the individual upright.

There are also risks of low blood pressure when an individual is sat upright from a flat position. The normal mechanisms to correct such blood pressure changes does not function very well, soon after a spinal cord injury. Hence there is a potential risk of less blood flowing into an already damaged area of the spinal cord and starving that area further, possibly causing further damage. This is especially relevant in those with a neck or high thoracic injury.

Bed rest may also allow any pressure sores to heal by avoiding pressure over the damaged area of skin.

If the spinal cord has been damaged it is unlikely that bed rest will lead to a full recovery, but it can bring some degree of recovery to some individuals.

It is not always helpful for patients and their families to rely on information found on the internet. No two injuries are the same and your doctor will give you all the information you need at the appropriate time relevant to you and your specific injury.

What happens to rehabilitation when I am on bed rest?

Rehabilitation still continues whilst you are on bed rest. You will be seeing the therapists: doing 'passive' stretches to your arms and legs; and carrying out regular chest physiotherapy, if needed. During bed rest passive therapy helps in maintaining satisfactory range of movements of the various joints and maintains the muscles and joints in good shape until 'active rehabilitation' starts, when you are mobilised out of bed.

Can I move whilst I am on bed rest?

Depending on the level and extent of your injury some people may be physically able to move about and others less so. If you have the ability to move in bed, it can be difficult to stay still, as it is natural to want to do as much as possible for yourself. The doctors will advise you about moving within the bed and what is safe for you. If necessary they will put you in a collar to restrict movements of the neck and head.

Whilst you are on bed rest it is important that the nursing team turn you from side to side at regular intervals. This is because it can get uncomfortable lying in any one position for too long and also to ensure that your skin remains healthy.

Being dependent on nursing staff/other people for everything

Whilst you are on bed rest, you will need to rely on the nursing staff and other people to look after you and do very basic things for you. This usually includes: needing help to toilet on the bed, washing, and getting you into a comfortable position.

Depending upon how much you can use your hands it may also include: feeding you, giving you drinks, organising your belongings, and turning over the TV etc. It is incredibly difficult for most people to need to depend on others, especially as you are used to being a completely independent and capable adult. This need to depend on staff is an essential part of staying on bed rest and allowing your body to recover. Do keep in mind that it is only relatively short term and as soon as you are able to get up out of bed, the staff will support you to regain as much independence as possible (within the limits of your injury). All patients here within the Spinal Injuries Centre are in the same position whilst on bed rest. This means that caring for you in this way, is something that the nurses are used to and for them is a 'normal' part of their job.

Sometimes it helps if you can talk to someone about your concerns. The staff may be able to answer some questions or concerns and help to reassure you. However, it is likely that you will need to wait and see how your body responds over the coming weeks and months, before you get more complete information about the situation. Some people find it helpful if they can talk about and share worries and fears with people close to them. Whilst you may not want to upset other people, it is likely that they are worrying about similar things to you and sometimes sharing this, helps you both to deal with it.

Worrying can be useful if it helps you to plan or act in some way. However, if you have done everything that you can and it is now just a matter of time, then too much worrying can become very unhelpful. Some people can get into unhelpful patterns of thinking and can find themselves going over and over the same thoughts or worries. Continuing to ruminate in this way can often make the worries grow and the situation seem worse.

If you notice that this is happening and you are finding yourself getting into these negative cycles, it can help to try to distract yourself and break the pattern. Try not to torture yourself unnecessarily by going over and over worst case scenarios or thinking about your greatest fears. This will not help and will only leave you feeling worse for it.

When we worry or feel frightened our brains send chemicals around our bodies to help us to take action. This can be really useful if we are in danger and need to act quickly. However, if you are unable to act and confined to bed this can become very unhelpful. Excessive amounts of these stress chemicals will not help our body in the recovery process, they actually make us more vulnerable to pick up infections. They can also lead to unpleasant physical symptoms, such as a pounding heart, rapid breathing, sweating, feelings of nausea, headaches, tension etc.

Stands to help to position things are available on the ward, so talk to the staff if you feel this would help you to read or use a computer or tablet. Please note that we have a limited amount of equipment, so you might want to bring your own resources.

Keeping the brain active

Some people enjoy a 'mental work out' and may choose to do puzzles such as crosswords, Sudoku and other brain teasers or watch quiz shows each day. Other people want to keep actively involved with work or home issues and may be able to do this via computer or telephone calls. We have even had one lady who decided to use the time to learn a new language, using an audio course!

Keeping a diary

Keeping a diary or notes about what happens each day, helps some people to get through this period of time and can help with keeping track and remembering everything that has happened.

Make the most of the opportunity!

Try to think of this as a rare opportunity to have time away from whatever you would usually be doing and occupied with. Try to think if there are any positive ways that you could use this time, for example watching films/box sets/books you have always wanted to, but never gotten around to. Could you make contact with friends you haven't had time to catch up with in a while? Is it useful to have time out to reflect on life and what is important? Some people make positive changes to their life, following this experience, rather than just continuing in the same way that they always have.

Managing difficult feelings

It is likely that you have lots of worries and concerns about your injury and what this will mean for the future. Being in hospital and confined to bed, you will have a lot of time to think about this, but will be unable to do a great deal about it.

This can be very difficult and frustrating. You may experience lots of different feelings including: fear, anxiety, anger, frustration, depression, despair, boredom, and many others. It is likely that these feelings will come and go at different times and all can be a normal reaction to being in this very difficult situation.

Many people tell us that they do not like to have to ask for things and worry about overburdening the nursing staff. Being able to communicate your needs and wishes is very important as it actually helps the staff to be able to support you in the most appropriate way. Please do not worry about asking for things and do let the staff know what you need. Sometimes it helps if you can ask for a couple of things, at the same time, whilst someone is with you. You may also want to remind staff or visitors to leave things in a position where you can reach them, before leaving you, so that you do not need to ask for more help shortly afterwards.

Needing to wait for someone to come, when you do need something can be extremely frustrating. In general, we do not find it easy to wait for things, especially when it is something simple, that you would normally be able to do immediately for yourself. Please bear in mind that there are only a certain number of nursing staff available on the ward, and there are other patients who are also relying on them for care. Usually the staff will check you are okay and if they are unable to help you straight away they will ask you to wait until they have finished with another patient or sometimes until another member of staff is available.

What can I do, whilst lying in bed?

Remember that by being on bed rest you are allowing your body to try to recover from what has happened. This in itself is a very important job. Whilst you may feel that nothing is happening, there should be lots going on inside you. Resting, lying flat and nourishing your body with regular food and drinks will enable your body to do all the necessary internal work.

That being said, whilst your body is busy on the inside, it is very difficult to know how to occupy your brain and give yourself something to do during this time. This is often the biggest challenge whilst confined to bed rest and lots of people can find it very difficult.

Below are some ideas that other people have found helpful:

Taking just one day at a time

Trying not to think too far ahead and just focus on what is happening today and how you will deal with it.

Breaking up the day into smaller chunks of time

Time can feel endless, especially when you are not getting up or having a change of scenery. Some people find it helps to try to find ways to break up the day, for example into the chunks of time between meals or turns or when the drinks trolley comes around. They may then plan to do different sorts of activities at different times of the day.

Keeping in touch with people

Having visitors can help to break up the day and to keep in touch with what is happening at home. Visitors can be really important, especially whilst you are on bed rest and reliant on other people to help you to do things. Some people enjoy the opportunity to catch up with lots of friends and people they may not have seen in a while. Others prefer to limit visitors to close friends and family, until they are able to get out of bed.

Some people find it helps to make a plan of who is visiting and when, so that you can try to spread out visits over the week, rather than everyone arriving at the same time. This may also reduce the pressure on your nearest and dearest to visit so frequently, if they know that you will have other people with you on particular days.

If it is difficult for people to come in to visit, there are lots of other ways of keeping in touch, including having regular phone calls, video calls or sending messages. There is free wifi for patients in MCSI. If you do not have a mobile telephone, there is a ward phone that can be brought to your bedside for you to use. If you need help using your phone independently, let staff know. We will always try to help you with this. We also have a technician from the Spinal Injury Charity, Aspire, who is available each week to help patients to use technology, such as setting up voice controls, so you can use your phone independently.

Supporting the people at home

There maybe things that you can do to support your loved ones, who are trying to keep things going at home and coming in to visit you. They may find it helpful to be able to talk to you about how they are managing. They may need your help or advice about how to do something that you usually do, or you may be able to make phone-calls or plan things which will lessen the burden on them, to some degree.

For some people it will be immensely helpful to be able to keep in regular contact and be able to talk through what is happening and try to plan things together as much as possible. This should also help you to feel more involved and to maintain your role as much as possible.

A change of scenery

Some people find it helps if they can have a change of scenery from time to time. You might find it enjoyable to have your bed pushed outside, into Horatio's Garden, if the weather is nice. There is also an indoor garden room, where you could spend time away from the ward, but sheltered from the elements. Talk to the nursing staff to check if it is possible for you to have some time away from the ward, on your bed.

Entertainment

Watching something on a tablet or mobile phone can be an easy way to occupy yourself and give yourself time away from the situation. Some people enjoy reading, watching films, using a mobile phone or tablet to play games etc. We have ipads that are available to borrow, if you do not have your own device. If you need help with knowing how to use any technology or are struggling to use this, due to difficulty using your hands, the technician from Aspire may be able to support you with this.

Some people enjoy listening to the radio or music or even listening to audio books. Looking at newspapers or magazines usually takes less concentration than reading a book, if you are finding it difficult to get into something for very long.