

CHAPTER 2

After the Hospital

In this chapter, you will:

- Learn the reasons for discharge and/or decrease in medical or therapy services.
- Learn how to find resources and information on brain injury.

Discharge and Reduced Therapy

Questions about Discharge

When you are discharged, you may wonder why you have to leave the hospital. This is a common concern and reflects people's fears about having to face how their lives have been changed by the injury. This may also be difficult for your family who may be worried about having to take care of you. These fears are often greatest when the injury has been severe, causing clear changes in your ability to think, get around, take care of yourself, and manage your feelings and behaviours. In these situations, the move out of the hospital is another major life change. Like many others,

you may have questioned discharge because you still had many needs and you felt the move out of hospital or rehabilitation was too quick.

One answer is that you may have gained what you could from your hospital or rehab stay, and needed to move on to make further improvements. Discharge from the hospital usually happens once you are medically stable; discharge from a rehabilitation ward occurs when your treatment goals have been achieved, or when the rehabilitation centre does not have the capability or resources to help you continue with your treatment goals.

You may have been discharged without being sent to a rehabilitation ward at all. That may be because you are not yet ready for the intense level of treatment offered. Those who are not ready may be sent to a long-term care centre or back home. To you, this may feel like your needs are being ignored. Remember, some individuals experience a slower recovery, but do improve to the point where they are ready for more intense treatment. It may take months or even years. When ready, you can begin treatment at the rehabilitation ward.

Returning home has benefits over staying in

hospital. You may discover strengths and weaknesses at home, school or work that would not be seen in the hospital or rehabilitation ward. These strengths and weaknesses can be brought to the attention of health professionals. Finally, going home is a chance for independence that is hard to achieve in a hospital or rehabilitation ward.

Dealing with Discharge

You can ease the stress of discharge by taking the following basic steps:

1. Ask the hospital staff if there is a discharge planner who can assist you with your discharge.
2. Get an **advocate**. An advocate is someone who will help you with some of the skills you have lost. They may help you organize your papers, take care of your finances, or help you get the supports you need. Choose someone who is good at the skills they will be helping you with. Choose someone who works well with you. If you have many needs, you may want to choose several advocates so that it is not too much work for one person.

3. Get organized. This is something an advocate can help you with. You may have lost your organizational skills or your motivational skills. You may find that you are just not well enough or too tired to deal with organizing your papers. You should start a binder or folder containing reports, handouts, notes from meetings and lists of names and phone numbers. Include anything that forms a record of your care and could be used to help you or your family members to better understand the injury and its effects. This information will also be useful if you need to give detailed information to your lawyer or rehabilitation centre.

4. When a problem arises, get in touch with someone who has provided care in the past. This could be your family doctor or a specialist, your lawyer, or a rehabilitation worker. It is often not until you return home or go back to school or work that you notice problems. This is the time to contact professionals who can help you meet new challenges.

Questions about Therapy

You may also feel your therapy is being limited. This concern usually arises when outpatient or community therapy, often

provided by an occupational therapist, physiotherapist, social worker, speech-language pathologist or recreation therapist, is reduced.

Many therapists believe that life is the best therapy. Healthy people need to take care of themselves, get regular exercise, and find interesting things to do. Instead of visiting a therapist, the experience of living motivates them; that is, life provides exercise, stimulation, and training. Life should provide similar benefits for you.

Even if you may always need someone to assist you in living, that person does not need to be a therapist. A family member, friend, home health aide, or community worker could assist you. You are your own best advocate because only you know your life goals, but you may need a group of people to help direct you. It is important to have people around who can encourage you to do the things you need to do.

Independence is another reason to move on. Therapists believe that limiting the length of therapy can help you maintain your independence. If you rely on a therapist to keep fit and active, you are not being given the chance to take care of yourself. Feeling

responsible for your own life can be a powerful feeling. People who have been given greater control over dressing themselves, feeding themselves, and doing everyday chores have shown amazing improvements in mood, conduct, and feelings of self-worth.

The Impact of Limited Resources

The final part of the explanation for discharge and/or reduced therapy is that there is limited service available; there may not be enough beds, or people to provide services. In rural or northern Alberta or in small communities, limits on available services may be the reason for discharge and/or reduced therapy.

In cases of discharge or reduced therapy due to limited resources, you will need an advocate to help you get better services. They may be able to help you adapt available resources to meet your needs. Go to your health board, band, political representative, local Alberta Brain Injury Network office (see Resources), or local brain injury association (see Resources) and ask how to get better services.

Finding Information on Brain Injury

Another frequent concern for survivors and their family members is finding information on brain injury. This is not to say that nurses, doctors, social workers, and therapy staff have not done enough teaching. They have likely given you information about diagnosis (the name given to your type of brain injury); prognosis (how you are likely to do after you leave hospital); continuing therapy in the home; keeping safe and well; dealing with future difficulties; and making arrangements for services in the community. For several reasons, you may still want to know more. For instance:

- There always seems to be more to learn. As you and your family face new challenges, the need for more information may grow.
- Information provided in meetings with hospital staff or community workers may not “sink in.” You may have been too tired or emotional to fully understand or remember it, or you may have memory or comprehension difficulties that prevent you from retaining information.

- You may want the “big picture”, meaning you want more in-depth information on brain injury, its usual course, common and not-so-common problems, changes you might expect in your family, how to return to school or work, how to begin volunteering, how to work within the health care system or other organizations, and so on. This type of information is usually provided a little at a time, usually when there is a specific problem or issue to deal with.
- Finally, there are times when the information you want just is not made available. This usually occurs when your stay in hospital is short, due to a less severe injury and quicker physical recovery.

Finding More Information

The solution to feeling uninformed is to gather as much information as possible. There are books, manuals, pamphlets, and videos your whole family can use. You can begin your search in the following places:

- Contact the local brain injury association nearest to you. Chapter 13 (Resources) has information regarding how to contact local brain injury associations.

- Search the Internet. Chapter 13 (Resources) has search tips to get you started.
- Talk to local health professionals or workers and volunteers at community agencies.
- Talk to your local Family and Community Support Services (FCSS) office and find out what specific resources may be available in your region. Dial 310-0000 toll free and ask for contact information for the FCSS in your area.
- Talk with other survivors and families of survivors who have gone through similar experiences. You may find their stories helpful and inspiring.
- Contact your local Alberta Brain Injury Network office. The Resources chapter has information regarding how to contact local brain injury associations.

In your discussions with others, do not be afraid to ask to have things repeated or explained more than once. The information may have been provided in the hospital or by a community worker, and it may have been repeated several times already - none of that matters. What matters is that you understand the information. Always feel free to ask to have information

repeated or written down. You could also ask people to say things in a way you understand. A good way to remember important information is to bring a tape recorder to record the meeting, or bring an advocate who will take notes for you.

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