

ALS



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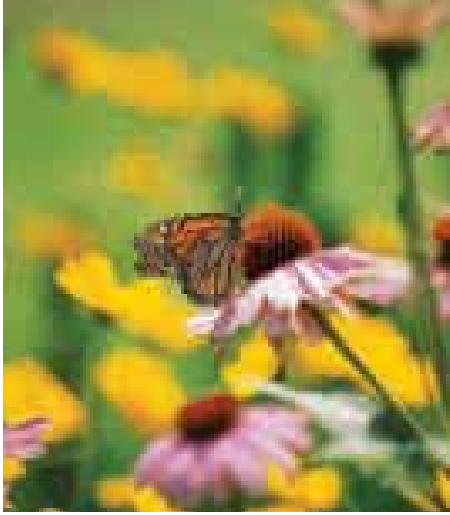
Acknowledgements

The ALS Society of Canada is indebted to the Motor Neurone Disease Association (UK) for their permission to adapt their original booklet for our Canadian audience. A most special thank you is extended to all of the young Canadian contributors who had the courage to share their personal experiences for the purpose of helping others.

Do you have a story to tell?

If you would like to share your own experience living with a parent with ALS, or have helpful advice to give others please e-mail the ALS Society of Canada at als411@als.ca. With permission your input may be communicated in future publications, or on the als411 web site, www.als411.ca.





www.als411.ca

Introduction

Amyotrophic Lateral Sclerosis (ALS) is not common, and it is unlikely you will know anybody else who has a parent or step-parent with the illness. Therefore, it is easy to feel you are the only one who has faced this situation.

This booklet has been produced with the help of a group of young people who do know what it is like to have a parent with ALS. They have all talked about their experiences, worries, and fears, and how they coped while their parent was ill. We hope you find this booklet helpful and that it makes you feel less alone. Not everything will be relevant to you at this time. Read the parts you think may be useful, and keep it nearby in case you want to know more in the future.

It may also be a good idea to show this booklet to your family and friends to help them understand how you might be feeling.

Contributors

Bryce, 13 and Kara, 15

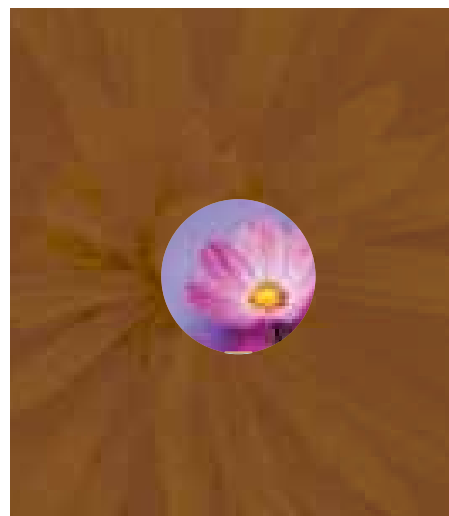
Bryce and Kara are brother and sister. Their dad was diagnosed with ALS when Kara was 12 and Bryce, 10. They missed all the regular things their dad liked to do, but they learned to see past the wheelchair. They saw the strong, tall man who never stopped loving them and who gave his all to the fight against ALS to help as many other people as possible.

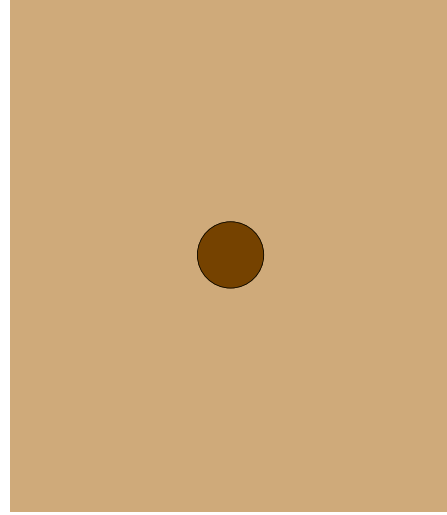
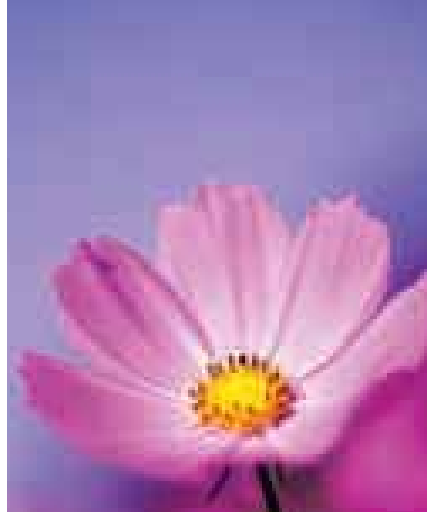
Evan, 16

Evan was nine years old when his dad was diagnosed with ALS. After five years of living with the disease, his dad passed away. To Evan, his dad was his hero who loved playing sports and going to the movies. Once ALS robbed him of those pleasures, Evan and his dad spent as much time together as possible watching sports and movies on TV at home and telling the same bad jokes.

Jenn, 20

Jenn's mother was diagnosed with ALS when she was 14 years old. Her mom died three years later. Being an only child meant Jenn had to take on all the help her dad required to care for her mom. She juggled studying for school, caregiving, and just being a kid. Not a day goes by she doesn't miss having her mom around.





Jordan, 23 and Shelly, 19

Jordan and Shelly are brother and sister in a family of six children. Their mom was diagnosed when they were 17 and 14. They were devastated at the thought of losing their mother. For two years, Jordan and Shelly helped care for their mother, but they coped with the situation in very different ways. One took on the role of caregiver with a high degree of participation while the other found the need to retreat more. Their strong relationship with their dad and their enduring faith helped them to get through their mom's illness and her death, and to be optimistic about the future.

Tracy, 23

At the time of her father's diagnosis, Tracy was 13. He died the following year so the family underwent many changes in a short period of time. Her dad had always been a very athletic man. Tracy and her older sister joined him in many activities. As the illness progressed, he could no longer coach them on the soccer field, so new ways to share in his teachings were found.

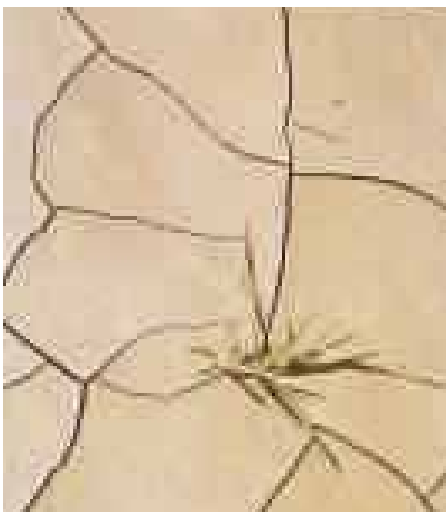
Vanessa, 19

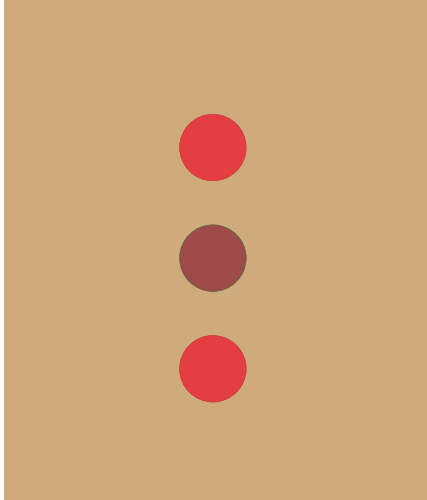
At the age of 11, Vanessa learned her father was diagnosed with ALS. He survived for several years. Along with her older brother and mother they were an unbeatable caregiving team. Vanessa's brother left home for university when she was in high school. She took on immense responsibilities with grace and commitment. Vanessa remains close to her dad to this day by reflecting on wonderful memories that keep him alive in her heart and mind.

Learning of your parent's diagnosis

You will probably remember quite clearly the day you were told your parent had ALS.

“My dad asked me if he could talk to me alone. I knew something was up. I started thinking of things that I might be in trouble for. When we went into my room, Dad told me that Mom had ALS. I asked him how that could be because the doctors already told us it wasn't ALS and that she would get better. He just told me they had been wrong and they had new information that made them think it was ALS. We just sat there and cried together for about 10 or 15 minutes. Mom was waiting in another room for me to go and talk to her. I mustered all of the courage I could, but as soon as I saw her I started to cry again and so did she. She asked me to sit on her lap and she held me like a little kid as I cried. Then she asked me to say something. All I could say was ‘you can't die. You will miss so many things that I need you to be there for.’ Then she just held me until I stopped crying.” **Jordan**





“I was so shocked that I could not even cry for a few minutes. But, oh, did I cry! I didn’t want to talk to Mom or even see her again because I thought it would be easier...but she made me. I sat on her lap while she was in her wheelchair and she held onto me as best she could while we cried together.” **Shelly**

“I remember that we knew our dad was sick. Our parents told us that we were hoping he had multiple sclerosis (MS), but there was another disease, a worse disease called amyotrophic lateral sclerosis (ALS) that he might have. I remember that he went to the hospital a few times for testing. One day after returning from the hospital Mom told us the doctors said Dad didn’t have MS. I knew that meant he had ALS and that he would die.” **Tracy**

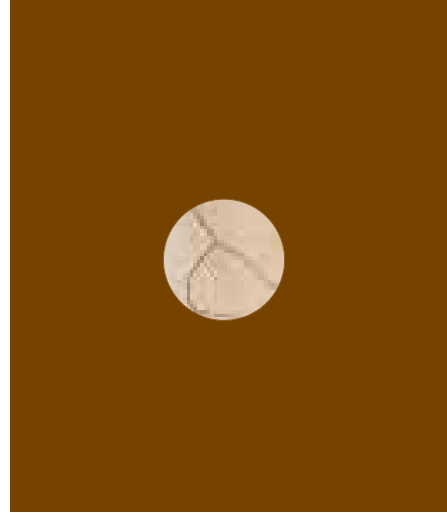
“I remember the day in late April, 2003. I had a softball game and my parents told me they couldn’t come and they had to tell me something important after the game. When I went home they sat me down and tried to explain to me that my dad was sick. They told me he had ALS. I had never heard of it or knew what it was so I was really confused. I can’t remember if Dad cried, but I think he did and I gave him a hug. I don’t think I really cried.” **Kara**

“I don’t remember the exact day my parents said my dad had ALS, but I vividly remember finding out that it was fatal! I started balling when I found out from the back of a booklet that my mom got from someone. My parents said he was going to be sick, would be in a wheelchair, and would lose his voice. They didn’t say it was fatal. That’s why when I read it I was so upset.” **Vanessa**

“I don’t remember a specific day or event, but I remember thinking things just started to change with our family and that things were going to be different. I just took things day by day and we still did a lot of the regular things with my dad when he was first diagnosed. As things progressed, that’s when I started to react more.” **Evan**

“My parents sat me down and said they had some good news and some bad news to tell me. They told me to tell them when I was ready to hear it. I didn’t want to know any bad news, so I didn’t ask. Eventually, they said they couldn’t wait any longer. They said my mom had ALS. I was oblivious to the diagnosis. I wanted to ignore it. The good news was they wanted us to take a trip together to Hawaii to spend some fun time together.” **Jenn**





It would not have been easy for your parents to tell you about the diagnosis – they were probably very upset and worried themselves, uncertain about what will happen in the future and perhaps knew little about the illness. Most likely they are trying to protect you from what is happening.

There is no right or wrong way to react when you are told that your parent has ALS, and no two people are the same.

You may want to know more about the effects of ALS.

“I was interested in knowing more. Lou Gehrig was one of my dad’s favourite baseball players, but I really didn’t know anything about the disease. A lot of people would come to our house like case workers and others who tried to give us information. I mostly learned from pamphlets and a bit on the internet.” **Evan**

“I wanted to know as much as possible. I did several projects about it in school. It made it easier knowing that other people had gone through this and my dad wasn’t the only one. To find out information I mostly used ALS web sites on the internet. As time went on not much went unanswered except how long my dad would actually live, but you can’t always have that answered.” **Vanessa**

“My sister and I went to the computer and put in an encyclopedia CD-ROM. We typed in ALS and a screen popped up with all kinds of complicated information and terminology. It said that people with ALS typically die within 2-5 years. I felt really sad when I read that.” Tracy

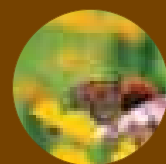
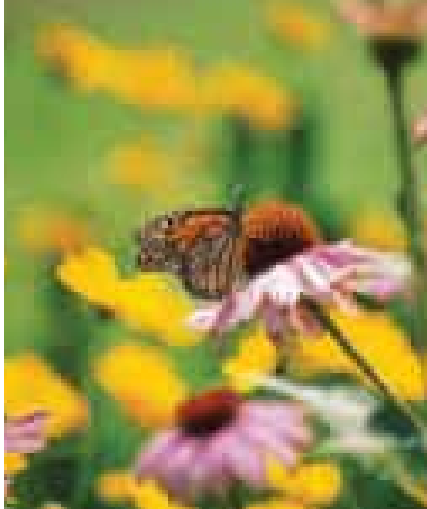
On the other hand you may feel that you do not want to ask questions about ALS in case you are told something you do not want to hear.

“Apart from the initial day when I used the computer, my parents were my source of information. They told us Dad was going to be one of those rare cases and we could hope for another 20 years together. I developed that mindset and avoided reading other information that would say otherwise.” Tracy

“I wanted to learn about ALS because I wanted to know what was going to happen, but I think I was afraid to find out.” Kara

“I pretty much blocked everything out and decided I only wanted to know more when absolutely necessary. Like when things started to happen where my mom needed more help. When she needed to start using a wheelchair I just wanted to know how to use it to help her get around, but nothing more.” Jenn





“I didn’t want to know more. I knew ALS was going to kill my mom and that was more than I wanted to know.” **Jordan**

But your needs may change...

“I asked my mom as much as she knew and I looked on the internet for more information.” **Kara**

“When I wanted to know something more I would ask my dad. We also had a really great family doctor who told us if any of us needed to talk to someone that he’d be happy to do it. But, it was good enough for me to get information from my dad.” **Jordan**

Your parents may be able to give you as much information about the illness as you need. Sometimes it may be difficult to ask them questions because you want to protect them and do not want to reveal how worried or upset you are. Or you may just find it impossible to talk to them.

If you want more information on ALS or about sources of support go to www.als411.ca.

Feelings

After a parent has been diagnosed with ALS you may find that life as you have always known it alters – your parents act differently, you feel different – nothing seems the same any more. Coping with the changes the illness brings may seem hard, but in time you will adapt.

Just as it hurts to learn that someone we love has been diagnosed with ALS, so the pain that person is feeling shows itself in different ways. If at times your parent seems to be too hard on you, try to understand their worries and frustrations, and be sympathetic to them.

“I was very unsure about things myself, but I would say to myself, ‘well if this is hard for me, think of how hard this must be for Mom, so just ignore me for now and just try to help her.’ ” **Jenn**

“There were times when my dad was upset, understandably. But he still liked to do the regular things. He coached me





in soccer for one year after he was diagnosed. I don't think his personality changed all that much. I still remember watching all the movies we loved to watch and he'd still tell the same old jokes." **Evan**

"My dad really changed after he was diagnosed with ALS. He was really angry. All of a sudden everything at home revolved around him. My mom couldn't leave the house without him kicking up a big fight. I just felt he wasn't the same person anymore and I really didn't like the person he had become. I felt bad for him, too, because he had to stop doing all the things he loved in life: playing soccer, golf, hockey, racquet ball, and jogging. My dad defined his life with those activities and once he couldn't do them anymore, he couldn't be the same person anymore. It was really hard." **Tracy**

"My dad really didn't act differently. We would joke that his most prominent traits were still there no matter how disabled he became." **Vanessa**

"I don't think my dad acted differently, but I know he started thinking more about helping other people and spreading awareness about ALS. That is one of the reasons I think he started the *On a Roll for ALS* event. That made me feel very proud of him—he was helping out and didn't want people to feel sorry for him." **Kara**

Their reactions may be confusing and frightening to you.

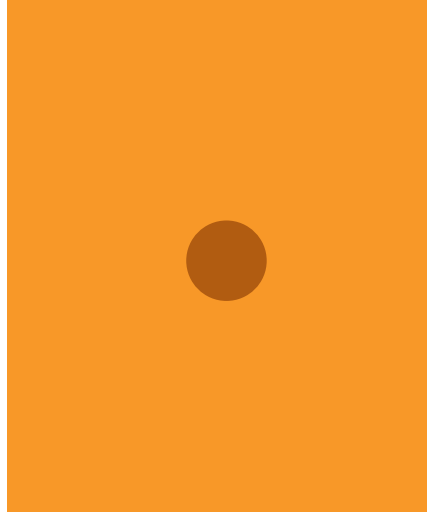
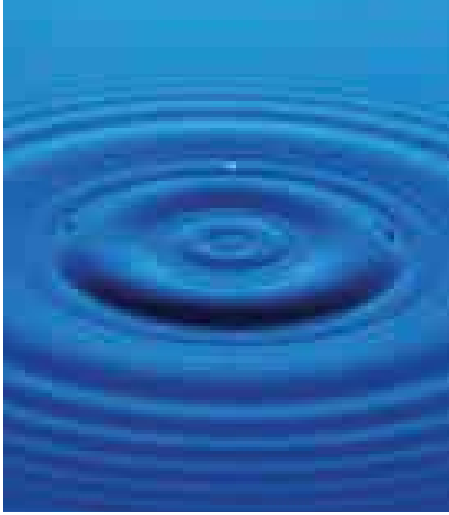
“My dad was very depressed, mad, and lonely at times. This made me feel scared and sad.” **Bryce**

“Dad was in construction for a living, so seeing him not able to do that physical work was strange. He was on antidepressants which helped, but sometimes he would get frustrated. Seeing him frustrated made us angry and frustrated. We also got angry at him sometimes because we didn’t always agree with how he was seeing things. We did our best to put ourselves in his position.” **Vanessa**

However, even when your parent behaves differently it is important to remember that underneath they are the same person you have always known and loved and their feelings for you have not changed. Try to treat them just as you did before they became ill.

You may also find your parents want more time alone together, to talk things over or do things they have always planned. This may make you feel excluded.





“Sometimes I felt excluded because I remember getting so mad when my parents wouldn’t come to my soccer games. Now I look back and realize it was so hard for my dad to travel and stuff.” **Kara**

“I didn’t really feel excluded. I think I knew that my mom was trying to protect me.” **Evan**

“My parents went on some trips together without me, but I thought it was fine because they needed to have some of their own time and it was really nice for them.” **Jenn**

“I never felt excluded. I had to mature faster than others my age because of the caregiver position I was put in. Dad’s arms went first, so right away I was helping him eat. It was more difficult for my dad to ask my brother to help him do some daily activities, so I was often asked to help with those things.” **Vanessa**

It is not only your parent’s behaviour and moods that change. You are also likely to be feeling varying emotions – angry that your parent has ALS, sad at what the illness is doing to them, resentful about the way it has changed your life, and worried about the future. Sometimes you may feel very mixed up and alone.

“I was scared, but I never really thought my dad would die.”

Bryce

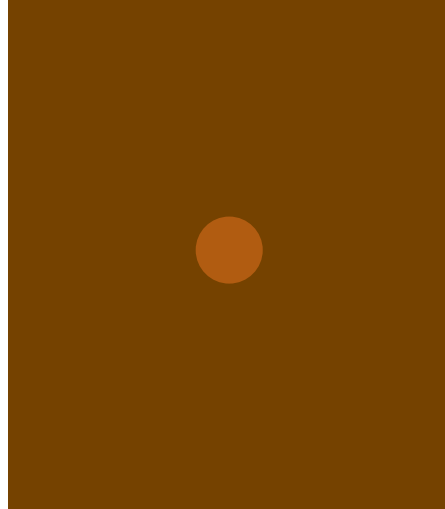
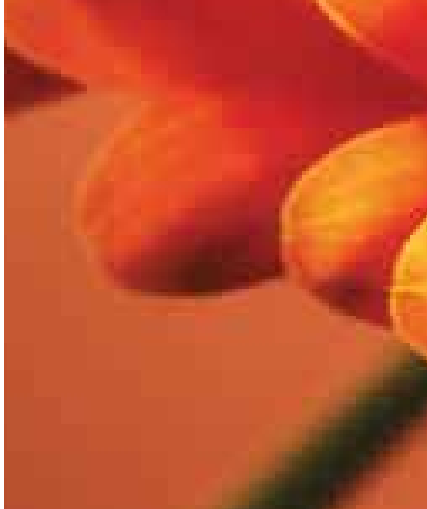
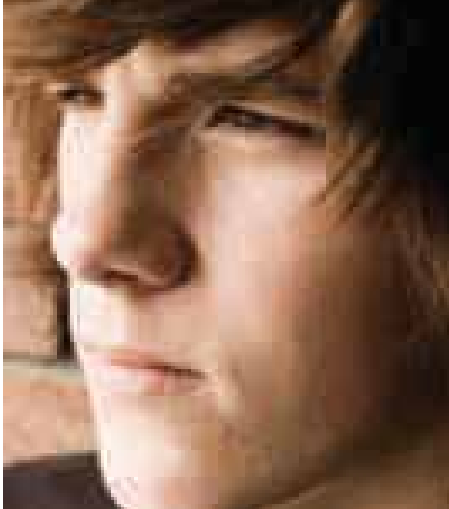
“I felt sad. It was tough to watch Mom die, and it was really hard to hear other girls talk about how ‘awful’ their moms were when they didn’t realize how great they had it.” **Shelly**

“A lot of the time I had to stay home from school to help, or I had to turn my friends down. I also had to give up dance because it got too expensive and I was too tired—it became a task, not an enjoyment. I was bitter!” **Vanessa**

“I was really upset that our lives were changing. I was mad at my dad for getting ALS. I knew it wasn’t his choice, but I was still really upset about the situation. I avoided my dad at all costs. I didn’t want to accept the fact that he was sick and seeing him stuck in bed (after he was bedridden) made it more real. I figured if I didn’t see him like that it would make things easier for me. Unfortunately, I know it made things harder on him because he wasn’t getting to spend any time with me. I really was in denial, I think.” **Tracy**

“I remember vividly there was a social worker that told us, ‘Your dad is going to die.’ I never heard it put as bluntly as that before. I remember thinking that we just have to hold out until a cure is found and try to stay healthy.” **Evan**





“I was sad. I don’t remember being angry or in denial. I was just so sad. How do you deal with the fact that your mom is going to deteriorate until she dies?” **Jordan**

“Sometimes I was scared, but I was never angry—just unsure. I was in denial for a lot of it.” **Jenn**

“I was really mad, like ‘Why is this happening to my dad?’ It’s so unfair.” **Kara**

At home too, it is not
always **easy to share**
your **feelings.**

“I hate myself for saying this, but I barely share how I feel, ever. If I did share when my dad was sick, I would mostly share my feelings with my Auntie or her daughter who is like my older sister—she is 16 years older than me.” **Kara**

“I really didn’t share my feelings much. But if I did, it was usually with my best friend or my mom’s sister.” **Jenn**

“If I was in the house, I tried not to look at, talk to, or be with my dad.” **Tracy**

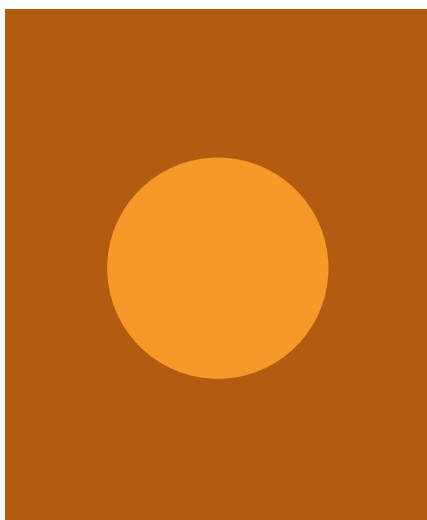
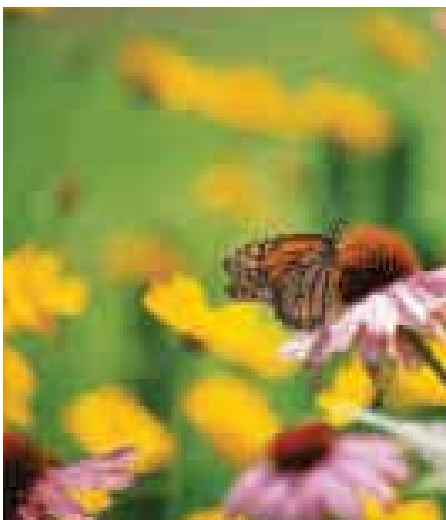
“Mostly I stayed away from the situation. I remember sitting in my room with my mp3 player listening to music for hours, doodling and daydreaming. I really locked myself up in my own world so that I didn’t have to deal with anything.” **Shelly**

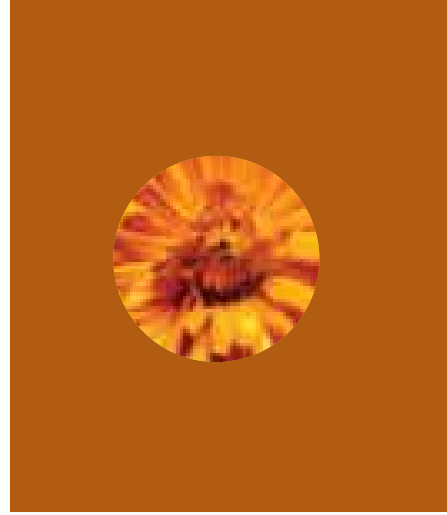
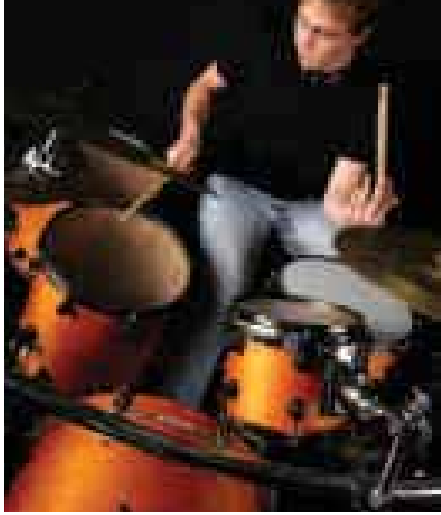
Different people find different things help them to cope – playing a sport, being with close friends, listening to music, going to a party, or having a good cry.

“I played a lot of music...piano, guitar. I tried to write my own music (laugh!). I wrote poetry. It helped me push my anger into a positive direction.” **Vanessa**

“I talked to my mom about the disease sometimes. Other times I would try to forget about it and hope that the whole thing would just go away. Somehow talking about it made it feel more real and I didn’t want that feeling to take over my emotions. I just wanted to be a normal kid. I started spending a lot more time with my friends and at their houses. Over there, I felt like a normal kid. I could laugh and play and not feel guilty. Of course, I always knew that ALS was waiting for me back at home.” **Tracy**

“I sort of just stuck with my friends to take my mind away from what was happening at home. It was a nice break just being a kid.” **Jenn**





“While Mom was sick I did write in a journal a lot.” **Shelly**

“I liked spending time with my friends because I felt like I could forget that my dad was sick and just have fun.” **Kara**

“There were particular friends that would listen to me and help me get things off my chest. I also had my mom and other people that came to the house to help. We went to a therapist a year before my dad died, but by then I had accepted it and didn’t really need the therapist, but it’s always nice to talk to someone. I also liked spending time with my dad watching movies and just knowing he was there. We could still communicate even though his ability to communicate was limited.” **Evan**

“I played sports, hung with my friends and rode my mountain bike.” **Bryce**

The effect *ALS* has on everyone in the family can put a strain on relationships, but we will talk more about that later.

As the illness progresses

ALS is a variable illness and affects different people in different ways. At the time of diagnosis it may seem that there is only something minor wrong with your parent – maybe a slight limp, weakness in a hand, or a change in their speech. However, over time, and it could be a long time, it is likely that their symptoms will become more noticeable. Certain events may occur which become ‘milestones’ for you and which you may find distressing.

“At first it was shocking when Dad lost his right arm function because we didn’t even know he had ALS yet. After we knew and the disease progressed, we didn’t really notice losses as much because we were so close to him and weren’t looking at it from an outside view. We were just too close to it to notice changes.” **Vanessa**

“At first my mom couldn’t use her right hand. She started using her left hand to eat. But I do remember one day her showing me how she cut herself shaving her legs...all the way up the back of her calf because she had to use her left hand.” **Shelly**

“My mom’s ALS progressed slowly over three years so it was relatively easy to get used to changes. But there were difficult moments like when I was feeding her and she would choke and the food would get all over my face. That was really, really distressing, like, ‘what the heck is going on?’ Or when I would give her extra support to help her walk and she would trip and fall. I would be freaking out when that would happen.” **Jenn**



“When I saw things happening to my dad I was like, ‘Wow. This is really happening.’” **Kara**

“I vividly remember once it was wintertime and I think it had only been a year or two since Dad had been diagnosed, and we went tobogganing. I remember Dad was climbing to the top of the hill and he fell and I had to pick him up. I was only 11 and he was still much bigger than me. We were with my friends, but I definitely wasn’t embarrassed or ashamed. I was like, ‘I just need to get my dad up.’ I was proud of my dad for going out and doing these things.” **Evan**

“At a soccer game I noticed that my dad’s ankles were turning inward. I was concerned and so was he. Of course, we would never have thought it would turn out to be something as terrible as ALS. I was scared when I saw the physical changes happening. My dad had always been such a strong man, and I didn’t want the disease to change that.” **Tracy**

“I remember one of the first things that deteriorated was my mom’s grip and her ability to walk. It was something so foreign to me because my mom had one of the strongest grips of anyone I knew. I used to think she could make someone’s skin bleed just by grabbing their arm! It was so weird and unbelievable.” **Jordan**

You may also be shocked if your parent starts to use a wheelchair, but as time goes by you will find you get used to it.

“When I saw the wheelchair I was scared that my dad wasn’t going to be able to walk anymore. It took a little while to get used to it.” **Bryce**

“For us it was a gradual thing. First my mom used a cane a lot and then she would use the wheelchair if she was going on longer walks. She went into it slowly, so I got used to it.” **Jenn**

“To be honest, I remember being embarrassed because Mom was no longer like the other moms and kids would give strange looks and seem scared of her. It was hard to see someone you love so much be treated so differently because she wasn’t the same as most people.” **Shelly**

“When my dad got a wheelchair I was happy for him because he was so excited to have a new toy. He bought the one that went the fastest and had the longest battery life so that he could go on long trips. At first, I didn’t want to go out with him when he was in his wheelchair. I thought that people were looking at us, and feeling sorry for me. Eventually though I got used to it. My dad would let me jump on the back and take me for rides. I really liked doing that because it was a lot of fun!” **Tracy**

“My dad started to use his wheelchair before he really needed it to get himself and us used to it. This made it a lot easier on the family.” **Vanessa**



“My mom was already in a wheelchair when I was told she had ALS. I don’t really remember this being a problem for me. I got used to the fact that my mom couldn’t walk. Sometimes it’s hard to remember when she did walk. It didn’t seem like that big a deal for me.” **Jordan**

“When my dad had to be in a wheelchair I felt sad. I don’t think I was embarrassed, but I don’t think I really wanted people to see him in it at first. After a while, I didn’t care... he was my dad and I loved him.” **Kara**

Some people
with ALS may have
difficulty talking.
This can be upsetting.

“There was a lot of adjusting. We went through using a lot of communication devices. We had the DynaWrite™ to begin with where he could press the buttons on the screen to say what he wanted. Then when he couldn’t point anymore, we had a laminated piece of paper with the alphabet on it. There would be rows and he’d nod. We would write the letters down with paper and a pencil. Then we couldn’t use that anymore so we got the speaking machine back again and hooked it up to a little switch on his knee. I know my dad would get frustrated trying to spell some things out. It was about being patient. Usually it was something important or funny to say anyway!” **Evan**

“Near the end, my dad started to lose his ability to talk. This made me feel so angry and frustrated because sometimes I couldn’t understand what he was saying. I knew it was frustrating for him, too. Some techniques we used were him using his head or eyes to point to things he wanted. Or he would open his mouth to signal he wanted us to suction him.” **Kara**

“We got frustrated with Dad because it was so slow trying to figure out what he was trying to say and what he wanted. He would get very frustrated. We started using non-verbal cues...blinking signals. He came up with a set of statements and we would go through them and he would blink when we got to the one he wanted to communicate. He also used a head mouse to control the computer. We also used speech generated technology, but it wasn’t his voice. He also had a call for help set up on the computer and he would tap a switch using his knee to activate it when we were in another room.” **Vanessa**

“We used a paper alphabet board and at first when Mom still had mobility in her arms she would point to the letter. Later, she had a laser pointer strapped to her head and used that to point at the letter squares. Eventually, with reduced mobility, even though the squares were large, she couldn’t keep the pointer on one spot for very long, and I would get confused. I’d sit there and she’d actually want a ‘D’ and I’d think she wanted an ‘F’ or something. It sort of got frustrating.” **Jenn**

You may find that even when others cannot understand what your parent is saying, you can. Sometimes you are just so close to someone that you know what they are going to say before they speak.



“It made me scared when my dad couldn’t talk, but I could understand him like no one else could!” **Bryce**

“My mother lost all ability to speak by the time she died, it was hard to deal with and it was very testing on your patience. It was very difficult, but I got to the point where I would just tell her everything, and if she had a question I would just use my knowledge of her personality and guess what she was going to ask and answer it without the question ever actually being asked.” **Jordan**

It is important to remember that although your parent may not be able to communicate very well, they can still listen! Even if the conversation is one-sided, you can always tell them the latest gossip from school, college or work.

Unfortunately some people with ALS need to go into hospital for a while. This can come as a shock when they have always been cared for at home and you are not used to them being so ill.

It is important that you talk to someone if you feel upset or worried by your parent’s illness. If you can, talk with family or friends or another adult you are close to. If you need to, you can always contact the ALS Society of Canada or your Provincial ALS Society and talk to someone there.

Being a caregiver

When your parent has ALS, you may find yourself helping in ways other children your age would never be expected to do.

“I helped a lot. I would sleep in my dad’s bedroom some nights to give my mom a break and help him in the wee hours. I would feed him, brush his hair, help him get into the wheelchair, in and out of bed, up and down stairs, go to the bathroom, keep his mouth moist, accompany him on hospital trips, and help him move around in bed so he didn’t get too stiff and sore. The hardest part of caring for my dad was when he was in the lift. He would be dangling from this pole and we’d have to push him to another room. I felt so bad for him. It must have been hard seeing his young daughters having to push him around like that. ALS really took his independence away. So unfair.” Tracy

“I helped feed, suction, communicate, and I entertained him!” Bryce

“I helped with everything—feeding, toileting, medicine, morphine pump. If my mom had to be away I would sleep in the same room as my dad and get up in the night to turn him. Basically, anything an adult caregiver would have done, I did it. When my older brother went away to university, I had to be even more helpful.” Vanessa

“I was there for pretty much everything. I helped my mom dress, bathe, eat, and we’d go shopping together for anything she needed. She was my mom, right? I never felt obliged to do it--it was something I wanted to do. Sometimes it got really stressful though and became overwhelming.” Jenn



“Lugging around all that equipment my dad needed was a bit time consuming. It was a pain dragging all the stuff around. We bought a van the wheelchair could go up into. Lugging that around—the lift—and getting him on it and bringing cases and cases of feeding supplies into the house was all just a bit of an annoyance.” *Evan*

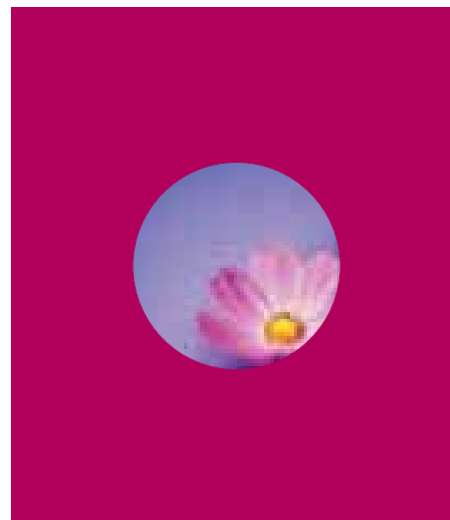
“I helped only when I had to. Mostly I just helped my mom find things.” *Shelly*

Helping to care for
your parent will mean you
have less freedom
than your friends.

“I would help feed my mom, sit with her and keep her company, or help with anything she needed when I was able to do so. It was so hard to feed someone. I often thought how ironic it was that I was feeding the person who once fed me. I also worried about choking. The best thing you can do is try to help the person remain calm so they can best use what little swallowing control they have.” **Jordan**

“My dad and I developed a system. When I came home from school I would help my mom eat dinner and get her ready for bed, and into bed. She had a call button to let me know if she needed anything while I was in the living room doing my homework until 1 am each day. My dad came home from work at 6 pm and would go right to bed to get rest. He would take over from me at 1 am until the homecare help came at 8am the next morning.” **Jenn**

“I was bitter because I couldn’t just be a typical kid in high school. I always had to have my cell phone on in case our case worker or a doctor’s office was calling. If my phone would ring the other kids would say, ‘turn off your cell in class!’ and I would think, ‘I wish I could.’ It made me feel good to help, though. People would say, ‘How do you do it?’ and I would always say, ‘well you just do. He’s my dad, so how could I not help?’ I think most people would do it if they were in the same position. My dad appreciated it, too, so that made me feel good.” **Vanessa**





“Sometimes it was awkward helping care for my dad because it felt like he should be taking care of me. But it made me feel helpful, too, because I was helping out my mom, and it made me feel happy because I was spending time with my dad.” Kara

“I never really wanted to help, but I knew it was an obligation. I wanted to just be a kid and do fun things. I felt spending time helping with my dad’s care took time away from my childhood and I was quite upset about that. Now I look back and wish I had done more. It’s funny how things change.” Tracy

“There was one time when I was invited to go to a friend’s to go swimming and I couldn’t because I had to help. I wanted to go, but I understood why I couldn’t leave. It was my responsibility. It didn’t happen that often, so it’s not like I could never leave the house or anything. I just knew that if my mom had to leave the house, I needed to stay home, so I’d stay home.” Evan

You may need to know more about the practical side of caring, such as lifting. Talk to your parents about asking a professional to show you the best way to do things.

“When we got a lift for my dad someone showed us how to use it. I remember it was a physically hard job getting the lift blanket under my dad’s body. Once it was there, it was easy to hoist him up, though.” Tracy

“My mom showed me how to do things like stick the suction tube down my dad’s throat. Sometimes he would gag and it made me feel very scared.” **Kara**

“We had someone who helped us understand what we could do to help and how to do it. But, it still didn’t make it any less nerve racking.” **Jordan**

“I learned by watching my mom do stuff which helped, but I was sometimes nervous and scared.” **Bryce**

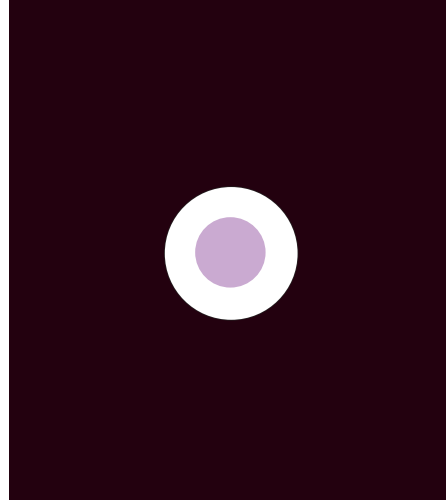
“We had a sling lift to help my mom get in and out of the bathroom. I was always afraid of hurting her, so it was nice when people would come in to show me how to properly use it.” **Jenn**

“Mom would help out while she could still talk. I was scared that I would hurt her especially because she could not control her emotions and she couldn’t hold back the tears if I had hurt her. It was an awful feeling to make her cry.” **Shelly**

“Our Community Care Access Centre case worker showed us what we needed to do while she was with us in the home, but then we were on our own after she left. We laugh now, but sometimes Dad got hurt because we didn’t do things right, but we learned!” **Vanessa**

It may be necessary for people outside the family to become involved with caring for your parent, and this can sometimes feel like an intrusion. It is easy to get annoyed if they do not understand the way your parent prefers to be cared for, or insist on doing things ‘their way.’

“We developed a system so when anyone else would come into the house to help out it would upset our routine and although they were trying to be helpful, it was more of a disruption for me and my mom.” **Vanessa**



“A great friend of my Mom’s was always there and she was amazing and good to talk to. However she did at times become annoying. It’s hard to have another person in your home all the time who isn’t family.” Shelly

“The problem was that the people that would come to help kept changing so you’d try to get used to someone and then they’d be gone and someone new would come in. There were lots of people coming in. I remember walking home from the bus and seeing five different cars in front of our house and thinking, ‘who’s there now?’ not even recognizing the cars. I was polite and nice, but I kind of thought, ‘I wish you weren’t here.’ ” Evan

However, having outside help can also be a very positive experience.

“It made me feel protected and happy that people were there to help.” Bryce

“It was nice to have people come in and help because it took some of the strain off me. They were able to give Mom the proper attention I wasn’t always able to give her.” Jenn

“It was a relief. Dad did so much for Mom and it was hard to see him always physically and emotionally drained.” Shelly

“We had some really amazing women who came in to help my mom. They made it easier for me not to feel like I needed to be with mom all of the time. They were loving women that will always have a special place in my heart for the help they gave in such a time of need.” Jordan

Not all parents want their children to care for them, and it is natural for you to feel left out if you want to help. Talk about this with them, if you can, and see if there are things they would be happy for you to do.

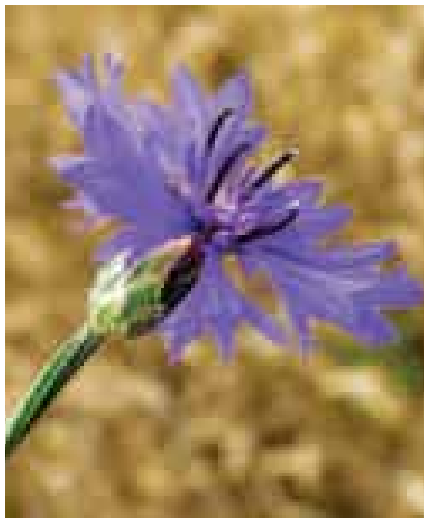
If you do spend a lot of time caring for your parent, remember you need to have a break.

“I played hockey, went mountain biking and hung out with my friends.” Bryce

“We did have a case worker and more private homecare near the end, so we could all take some breaks—about two hours a day during the week. Someone would sleep over sometimes to let me and my mom get some sleep.” Vanessa

“I went to Air Cadets once a week. That was really helpful. I was always really ecstatic when I got my breaks!” Jenn

“Sometimes a break was just leaving the room and relaxing, or watching TV. The break was not being 100% responsible, which was nice.” Jordan



“I would get time to do my normal things like go on the computer or watch TV. But I felt guilty because it felt like I was giving my mom so much to do.” Kara

You may feel concerned about going out, or leaving home to go to college or university. But your life must go on.

“I felt guilty about going out with my friends because I would think, ‘what if this is the last time I could have spent with my dad?’ Bryce

“Since my mom died I feel a bit guilty about the breaks I had when she was living. Sometimes I think maybe I should have been there to do something for her instead of being away.” Jenn

“I felt guilty when I had breaks because I didn’t help all of the time, just sometimes. I told my parents no if I didn’t want to help. I just felt uncomfortable with it. They actually encouraged me to help more.” Shelly

If you have an opportunity in your life which you want to take but it means you will have to leave home, talk to your parents about it. The chances are they will be supportive and know that you will come home if you are needed.

“My mom was really proud of me for my participation in the Air Cadets. She was so proud when I’d come home and tell her I got the best marks on my uniform, or was chosen to do this or that. She was always like that.” Jenn

“My parents were great. They let me know that I needed to do things for myself, too. They encouraged me to get a job and save some money and work towards my future.” Jordan

Relationships with parents

The relationship with your parent is special and that is why being told they have a serious illness has such a huge effect on you. They will also be worried about you as much as you are worried about them.

The worries and stress of the illness, and the changes it brings, will have an effect on everyone in the family and may cause difficulties in your relationship with your parents.

“During the time my dad was sick my mom and I really didn’t get along and I feel so bad about that now.” **Kara**

“I was so upset that my dad was sick. I began to avoid him altogether. I wanted to remember him as he was before ALS. I figured that by not seeing him, I could keep my memories of him alive and more positive.” **Tracy**

“My dad was really stressed out—this was his best friend in life he was losing. He would go off downstairs into his study for awhile. I would just leave him be so he could have his alone time.” **Jenn**



“I stayed away from my mom. I know it was hard for her, but I didn’t know how to act, so I just cut the relationship off, more or less.” **Shelly**

But a **new kind of relationship** can develop.

“I was always close to my mom who was the caregiver, but caring for my dad together brought us even closer. We call each other ‘best friend.’ We went through so much together.” **Vanessa**

“I got much closer with my mom. I was scared that something bad might happen to her now that my dad was sick. I couldn’t face anything happening to her so I stayed by her side whenever I could. I was going to lose my dad, I knew that. But I was not going to let anything happen to my mom.” **Tracy**

“I got much closer to my mom because we spent so much time together and she came to depend on me for a lot. As for my dad, I think we’ve gotten closer since my mom passed away because there is a huge void there for both of us and we are able to talk about it together now.” **Jenn**

“I learned to talk to my dad more about my feelings and realized how much he loves and looks out for all of us.” **Shelly**

You can find ways of staying close to your parent who has ALS.

“I would bring my keyboard or guitar into my dad’s room and play for him. He was really proud of me. We had more time together than most kids my age do with their parents. We knew the time was limited so we made the most of it.” **Vanessa**

“We used to spend a lot of time together playing soccer. My dad was my coach. So we shifted from soccer to watching more movies together.” **Evan**

“I had a book written by a person with ALS and pretty much every night I would read a chapter to my dad. I also watched the Vancouver Canucks games with him.” **Kara**

“My mom liked to do word searches my aunt would cut out of the paper for her. I liked to sit with her and watch and help her if I found a word. I also took her shopping when she didn’t feel like sitting at home.” **Jenn**

“When Mom got to the point where she couldn’t talk or move much, I would hold her hand and tell her about my day. When the person you are talking to can’t ask questions it’s really hard to talk about that for very long, so when I ran out of things to say I would read her a book. She loved the *Little Critter* books, by Mercer Mayer, so I read her whole collection to her in the last couple weeks of her life. And she had a lot of those books.” **Jordan**

Physical contact, like hugs and kisses, is a good way of showing your parent how much you care about them and how special they are to you.

“I could have done more to show Mom I cared. But she knew. I gave her a hug and kiss and told her I loved her before I left the house, every time.” **Shelly**

Although your parent’s physical condition may change, and your relationship with them may be different, remember some things do not alter.

“My mom was still so caring towards other people. She worried more about other people than herself. It was

reassuring because so much else changed. It was nice to have those little things to remind you of how Mom was before ALS.” **Shelly**

“As often as possible we would take my dad to watch our local Junior ‘A’ hockey team’s games. He kept his season tickets which helped him feel like he was maintaining some independence and was still part of living in the community.” **Vanessa**

“We still had the same jokes and watched the same movies. We must have watched *Star Wars* a thousand times a day! My dad’s sense of humour and his love for sports and movies never changed.” **Evan**

“Her smile! No matter what was going on, my mom would always have a smile somewhere in her. She was a really sweet person.” **Jenn**

“It’s hard to keep the same relationship with someone who can no longer talk or move, but the love is still there. In my case, the relationship I had with my mom was really good and strong right to the end of her life. She was always someone I could talk to and count on for advice even when she was sick.” **Jordan**

“My dad was always a funny, outgoing guy and he stayed like that even when he got sicker. I loved that about him.” **Kara**

“My dad’s interest in sports stayed the same. Even though he wasn’t my coach anymore, he still came out to my soccer games and supported me. He would charge up his wheelchair and travel through the city over 30 minutes to get to my games. His passion for sports never lessened. In fact, I know that’s what he’s doing now in heaven...” **Tracy**

Relationships with friends

You may find that you can talk more easily to your friends than your family.

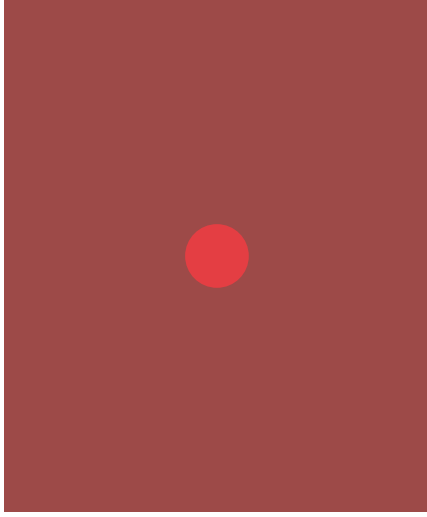
“I didn’t want my friends’ sympathy, but if something was really bothering me, I knew I could talk to them. I mostly just wanted to play and have fun, but I knew they were there. Definitely.” **Evan**

“I could talk easily to my family, but I had a few friends who were great at listening. They tried to understand and wanted to understand.” **Vanessa**

“It was easier to tell my friends things because they didn’t understand. I could express myself about the little things and explain everything...that helped. With my family it was hard because everyone did know how tough it was and sometimes it was too difficult to talk. It was too upsetting for all parties.” **Shelly**

“I found it easier to talk to my family because I knew that no matter what they were always there.” **Bryce**





Or you may find it difficult to talk to friends.

“I didn’t like to talk about ALS with my friends because they would ask too many questions. It seemed as if they were being nosy and wanted to know all the details. I preferred talking to my family who knew the situation and didn’t need continual updates.” **Tracy**

“I found it was easier to confide in family than anyone else. Outside sources are good, but I didn’t have many and there were even fewer people than I thought I could talk to about my mom and the disease. I would talk to my dad mostly and that was all I needed.” **Jordan**

“I found it much more difficult to talk to my friends. I felt they wouldn’t know what to say to help me out.” **Kara**

“Other than my best friend, I didn’t really think my friends could understand because none of them had ever gone through anything like having a parent with ALS.” **Jenn**

It may not be so easy inviting friends home

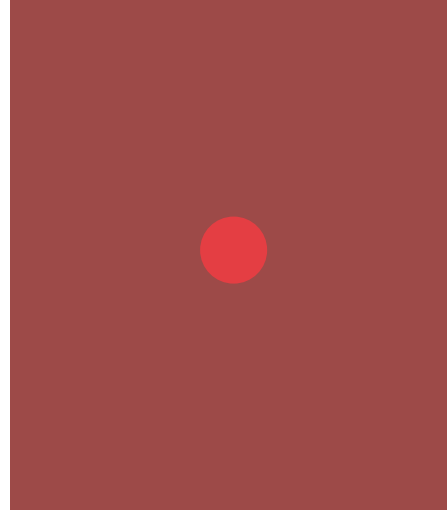
“I absolutely didn’t want my friends to come over and know the seriousness of what was going on at home! I thought if they knew what was going on they might feel sorry for me and start treating me different. I didn’t want that. My dad didn’t want many people seeing him anyway.” **Tracy**

“Sometimes I didn’t want people to come over because they would see the pain my family was in.” **Bryce**

“I never felt like I didn’t want to invite friends over, but once my dad was bedridden, he didn’t feel like meeting new people. He knew my best friends, though.” **Vanessa**

“I didn’t have time to entertain my friends. Taking care of my mom in the evening just took too much time to invite people over.” **Jenn**





On the other hand...

“My friends were over all the time. I was never embarrassed by my dad. I had a regular set of friends who weren’t scared by machines and wheelchairs. They knew my dad.” **Evan**

“I was happy to have people over to my house and I would happily take them into my mother’s bedroom and introduce them to her. It didn’t bother me that she was sick, she was still my mother and I was proud of that.” **Jordan**

“I was fine with having people over, but I was a little embarrassed when Mom would make loud noises to get our attention when she couldn’t talk.” **Shelly**

No matter how you feel at the moment, do not be too quick to dismiss your friends’ support. To help them understand what you are going through, why not let them read this booklet and answer any questions they might have.

Talking things over

There may be many times when you feel you really need to talk things through with someone. The pressure of caring, both practically and emotionally, may become too much for you, or maybe you just need a good cry.

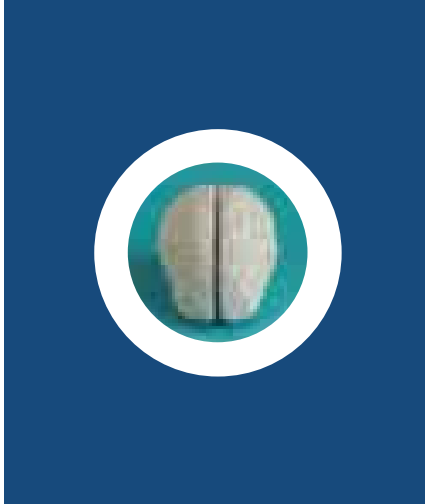
Even if you know you can talk to your parents, there may be specific worries you find difficult to discuss.

“My family seemed to want to keep my dad’s illness hidden, but I didn’t understand why we had to keep it a secret. Even some of our close family friends weren’t told that my dad had ALS until he had died.” **Tracy**

“I kept a lot inside, but I told my boyfriend when I was worried.” **Shelly**

“I had some feelings inside that I couldn’t get out with my family. That was why I went to a therapist. I didn’t have resentment toward my dad, but the burden his ALS put on our lives, I resented that. I had to talk to a therapist to get that off my chest.” **Evan**

“I would mostly keep my worries to myself. Most of the time someone else would bring them up, or my dad would figure something might come up and he would end up giving answers to unasked questions. It made it easier that way.” **Jordan**



You may fear that talking about your worries or feelings to your parents will open the ‘flood gates’ and you will lose control of your emotions.

“There were times I felt like talking, but I didn’t really know what to say. I mostly kept my thoughts and feelings inside, which I regret doing.” **Kara**

“I was upset, but I didn’t want to make my family upset. Once we had a girls’ night out at my aunt’s house. We were watching a bunch of movies and I don’t remember what it was that triggered it, but I felt so stressed and just got up and went to the kitchen and just started to cry. My mom, aunt and cousin ended up coming in and they started crying with me. It was like, ‘OK, this is what we’re all going to do tonight’ and it was fine. My aunt was really supportive. I could talk to her about anything and she’d always be there for me.” **Jenn**

Try to find someone who will really listen and try to understand what you are going through. Talking and sharing your feelings can really help. Listen to other kids who know from experience, like the young contributors to this booklet.

“Try not to keep things bottled up inside. It is so much better to communicate with your family...I wish I could have done that.” **Kara**

“My advice to families is to be open with each other and to keep an eye on one another. Some family members might have a big problem with the whole situation, so it’s important to let them know the home is still a place to come and be comfortable and cared for.” **Jordan**

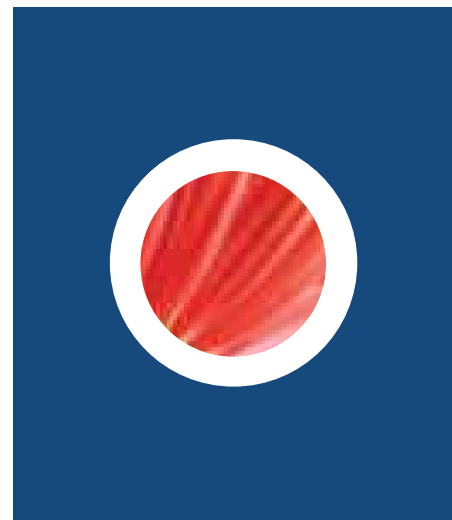
“Be honest with each other. Try not to sugar coat your feelings, because you might not get the help you want and need. It’s best to be open with your emotions so that you can be helped by others.” **Tracy**

“Talk as much as you feel comfortable doing, and maybe even a little bit more. It’s hard to talk about some things, but it is okay to cry and feel like things aren’t fair or right. It would have been nice to know other people who were going through the same thing. I still do not know anyone who has personally dealt with ALS like my family has.” **Shelly**

“The more you don’t talk, the more it will hurt you.” **Bryce**

“I recommend not hiding things. I understand about my parents not telling me ALS was fatal in the beginning to shelter me, but I feel knowledge is power. The more you know, the less surprised you’ll be when things happen. Talk as much as you can about what might happen before it does so you can be prepared.” **Vanessa**

“I think counselling can help. It’s different than talking to your parents because they (counselors) are professionals and have seen this kind of thing before, so they know what



to do. They knew I had feelings I needed to get out in the open. Also, try to be as open as possible with your family. Be supportive of each other. Being a good, solid family unit helps.” **Evan**

“My dad and I think families should set aside a special time each week to just talk things over. It could even be while playing a board game or something. Just make that special time.” **Jenn**

Bereavement- death and dying

It is not easy to consider, much less face up to, the possibility of your parent dying.

“It’s not something I thought about much because there was so much around the house to keep me busy with him. I put it out of my mind as long as I was busy, but it was always in the back of my mind.” **Evan**

“I thought positively until the very end and I think it helped me recover when my dad did die.” **Bryce**

“My mom and dad were both holding out for a cure so we didn’t talk much about death. Once it became apparent that my dad was going to die, we still didn’t talk about it because then it was just too sad.” **Tracy**

“I tried not to think about it, but I kind of forced myself to think about it because I knew it was a reality and it was eventually going to happen.” **Jenn**

Or you may think about it often.

“It’s horrible to say, but sometimes it got so tough for us that we would say to ourselves, ‘when is it going to end, when is he going to die?’ but of course we never really wanted that to happen.” **Vanessa**

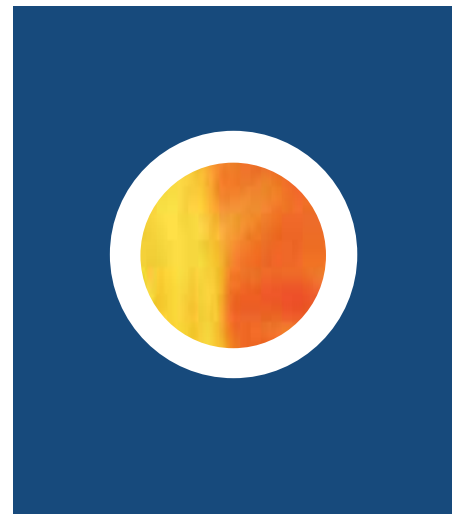
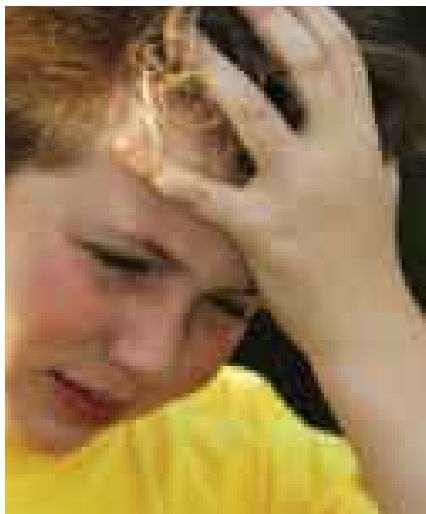
“I did think about my dad dying sometimes, but I didn’t want to believe that someday he really would be gone. I talked to my auntie and my mom about these worries.” **Kara**

“I knew my mom would die. It was the worst thinking that even before she died she wouldn’t be able to speak. It was also so difficult to think that I wouldn’t have a mother at those important times of my life like graduation, getting married, and having my first child.” **Shelly**

“I really didn’t worry too much because I have a very strong faith in God and an afterlife where I will see my mom again. I found that to be very comforting. It makes it easier in situations like that to have a faith system that gives purpose to this life.” **Jordan**

Even when you know someone is very ill and they are not going to get better, their death can still come as a shock.

“A nurse had told me that my dad was going to die soon. It was a shock when my mom woke me up and told me that my dad had died during the night. Even though I knew it was



coming, it still felt so abrupt. It's hard to explain. You think you're prepared, but you just never really are." **Tracy**

"I was shocked because I always thought there would be a cure." **Bryce**

"One night I was doing my chemistry homework and my mom rang her call button. I was actually almost annoyed because I was trying to get my work done. I went to her and she was frantically telling me to call 911! That's when it hit. It was like 'boom' here it is. I freaked and went downstairs to get my dad because I just couldn't physically make myself dial 9-1-1. No force on this earth could make me do it. She didn't die that night, but she did three days later. I was in shock those three days. It was kind of surreal. She died early in the morning on the third day. When I woke up, I knew by instinct she had just passed away. It was ten minutes after she died. There was just something drastically different about the house." **Jenn**

"The night my dad died he was so sick—I knew he was going to die soon. I found out in the morning. It just shocked me that he was actually gone." **Kara**

"It wasn't so much shocking as painful. After a long process of thinking it through, my dad decided one Monday that was the day he was going to stop using his BiPAP® ventilator and let nature take its course. We begged him not to, but we also knew he knew what was best for him. We had 40-50 people at the house the day he decided to do this. He took off his mask in the morning of June 22nd and he died at 6:43 am June 23rd. It wasn't a shock it was just painful and hard to see." **Vanessa**

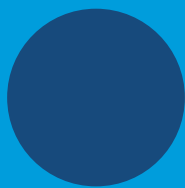
"I wasn't shocked. It was very obvious right before she died that she was going to. You could feel it in the atmosphere

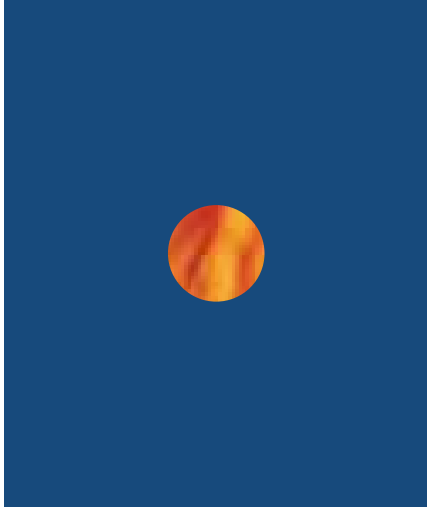
You may experience a **mixture of emotions.** You may even feel relief which is a **normal response.**

of the house, it was solemn and you could just tell it was coming. I remember coming home from work the day my mother died. I was working at night and really should have gone to bed but I didn't want to. I just wanted to be with her. It was as if I knew she was going to die while I was sleeping, so I thought if I didn't sleep she wouldn't die. I sat with her until noon when my dad told me to go to bed to get the rest I needed to get through the next night of work. My Dad woke me up at about 4 pm to tell me my mother had just passed away.” **Jordan**

“The first time I really saw my mom cry was the morning she came in to tell me my dad died. We cried. It was an emotional relief to see him not being held back by ALS anymore.” **Evan**

“I was really relieved that Mom had passed. She had suffered so much and even though it was sad and hard, it was better for her to be out of the pain and off to a better place than here with me suffering.” **Jordan**





“I felt relieved when my dad died.” **Kara**

“It was a relief. It was like we could finally move on. Before, we couldn’t plan anything for ourselves like missions for our church, trips, vacations, school, etc.” **Shelly**

“I felt relieved for my mom. She was the one who did most of the work and was so exhausted at the end. She needed a break so badly. I was also ready for life to get back to normal although it was going to be a very different normal than before.” **Tracy**

“When I knew my mom had died I felt a little bit of relief because I knew she was struggling so hard. She was in a horrible state when she passed away so it was a relief she wasn’t in pain anymore.” **Jenn**

When someone you love dies, you feel many different emotions. Some may not last very long, while others will probably be there for a long time, maybe forever.

“It’s been two years. Not a day goes by I don’t think about my dad or miss him. A lot of things remind me of him and I try to hold onto those. Because we watched a lot of movies I just picture him as one of those heroes from the movies.” **Evan**

“I feel like I should have spent way more time with my dad. I also really wish I could hug him again. He was so tall, when he hugged me I felt so safe.” **Kara**

“I know people say the pain will go away, but it doesn’t. It’s still as strong today as the day my mom died, but you do find ways of coping with it. I can ignore the pain for a couple of days while I concentrate on work, but by the end of the week I need some time by myself to just cry a little bit.” **Jenn**

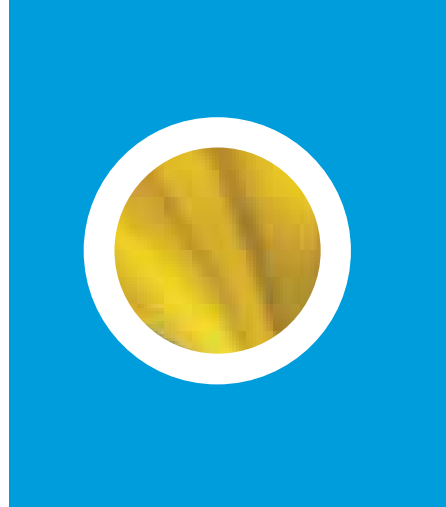
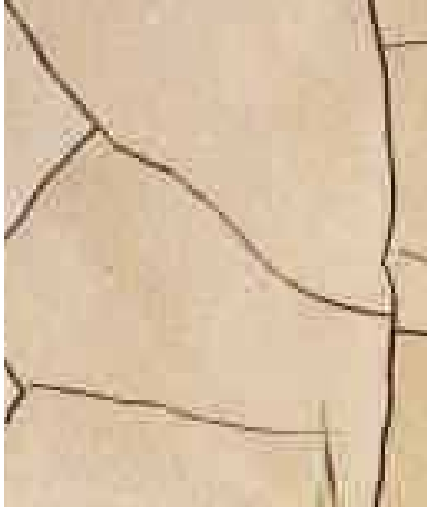
When your parent dies, it may seem as though your world has just fallen apart, and it does take time to adjust.

However the people who have contributed to this booklet are proof that life can, and does, go on. They remember the good times, before and after their lives were affected by Amyotrophic Lateral Sclerosis.

“It’s been two years and we still miss him and cry. I was just watching family videos of our extended family making tomato sauce. We would all get together and it was like a big party. I have a new boyfriend and I said from the beginning that I wanted him to watch these videos so he could know my dad. He’s watched them and he comes to the cemetery with me, so he understands what a big part of my life my dad still is.” **Vanessa**

“I feel like I learned a lot from my mom being sick. I miss her and think of her often, but wouldn’t change anything. I’m happy she is not suffering still—we don’t want that and she didn’t want that. I would advise kids going through what I went through to keep a journal and be involved in positive programs. For me it was my church youth group. Honestly, my faith has made all the difference for me.” **Shelly**

“My dad’s been gone a year and a half now and I miss him, but I have a lot of fun memories and I know that he is still with me.” **Bryce**



“My mom died four years ago. I still miss her sometimes and I get a little choked up when I think about it. I have dealt with it and I am optimistic about life. When I look back at that time, I am just happy that I got to spend as much time with her as I could.” **Jordan**

“Since my mom died, I went to school and now I build sheet metal for aircraft. I want to get my pilot’s licence some day. I got my glider pilot’s licence through the Air Cadet Summer Camp. It’s a lot of fun. One thing I would like to say to kids reading this booklet is if they have a favourite activity or special interest, just go for it! **Jenn**

“I still hate that our family was affected by this disease. But now, I can see some of the good that has come out of it. I’m a lot closer with my family now. I cherish the time that I can spend with the people I love. Losing my dad to ALS helped me realize nothing is forever, so you have to live in the moment and never take life for granted.” **Tracy**

Do you have a story to tell?

If you would like to share your own experience living with a parent with ALS, or have helpful advice to give others please e-mail the ALS Society of Canada at als411@als.ca. With permission your input may be communicated in future publications, or on the als411 web site, www.als411.ca.

Provincial ALS Societies

ALS Society of Alberta (and NWT)

1-888-309-1111

www.alsab.ca

ALS Society of British Columbia (and Yukon)

1-800-708-3228

www.alsbc.ca

ALS Society of Manitoba

1-866-718-1642

www.alsmb.ca

ALS Society of New Brunswick

1-866-722-7700

www.alsnb.ca

ALS Society of Newfoundland and Labrador

1-888-364-9499

www.envision.ca/webs/alsnl

ALS Society of Nova Scotia

1-866-625-7257

info@alsns.ca

ALS Society of Prince Edward Island

1-866-625-7257

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ALS Society of Quebec

1-877-725-7725

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