



When everything changes
because of diabetes

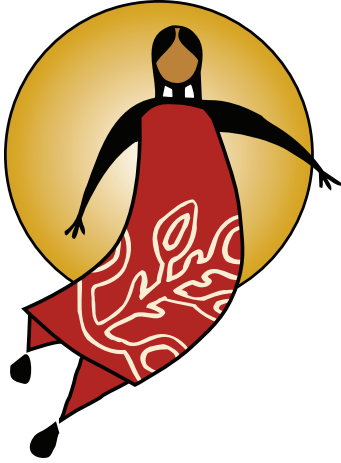


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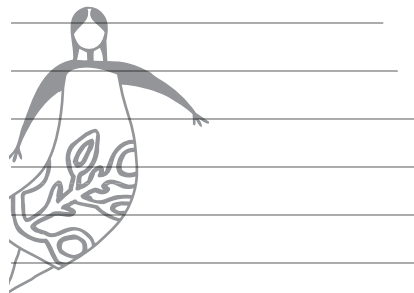
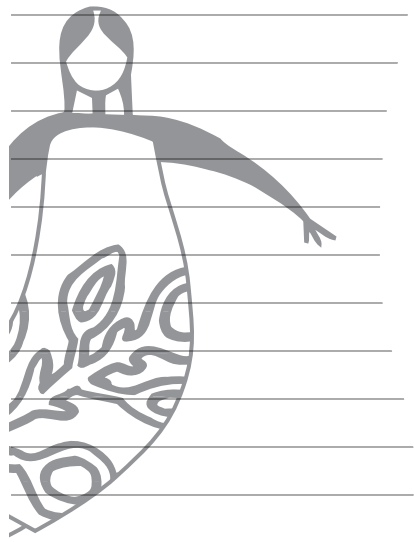
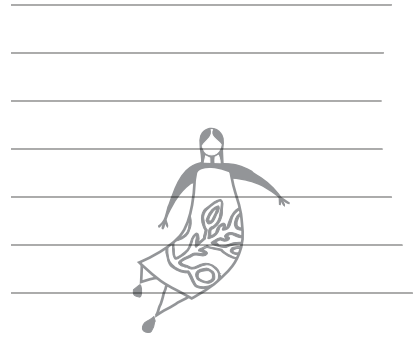
Theme 2: When everything changes because of diabetes



Before reaching her mid-thirties, Margaret did not know what diabetes was. When she first got it, she couldn't care less. She then had to take fairly high doses of medication. Now she's proud to say that she can control her diabetes through exercise and diet, and that she has decreased the amount of medication that she has to take. Of course she was afraid at the beginning, and she still has fears, particularly regarding her hands and feet, which she watches very carefully. As for her diet, she admits that she had to make sacrifices, and has given up some of her favourite foods and learned to eat the things she never used to like. Whenever she is invited over to a friend's place, she rarely lets herself be tempted by a piece of cake, reminding herself that she is the one who will have to suffer the consequences - she will feel really ill, exhausted and "run-down." What is her secret for keeping her moral up? She tries not to dwell on the idea that she is sick. "When you keep reminding yourself that you're sick, the sickness tends to get blown out of proportion," she says. In her opinion, you have to learn to help yourself and think about yourself above all else, because it's so hard to follow a diet and to give up everything that you used to like.



1. Why is there diabetes?



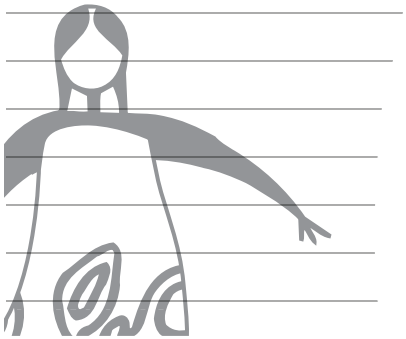
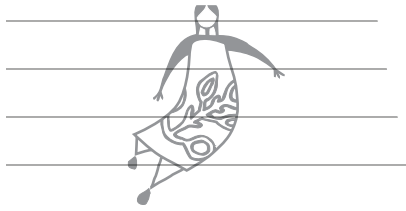
Now when she talks about it, she believes that diabetes probably appeared in her community when people started to become inactive, unlike in the time of their ancestors. Then, all travel was by canoe or on foot, whereas today people do everything by car or snowmobile. Margaret found a renewed desire to go for walks, whether in the village or in the forest. Because she is working full-time, there are limits on her time and she cannot always find time to do her favourite activities. To manage, she takes things one at a time. Whenever she can, she likes to set up camp in the bush, where she has to everything on foot. She has stopped counting the years and watching the clock. She doesn't feel obliged to make huge meals for the whole family for the holiday season. If, her children, who are now big enough, want to see her at that time of year, they know where to find her- in the forest. At her job, she tries to delegate the work that she cannot do alone. She refuses to carry all the burdens on her shoulders. This is not because she wants to be mean or selfish, but simply because she does not have the time or the energy. She has also had to set a limit on how often she will baby sit the grandchildren, as she is constantly requested to do by her children. She knows her limits and tries to make sure that they are respected by her family. In spite of all this, she still feels anxiety. When that happens, she does relaxation activities. She would very much like to help other diabetics and share with them her experience of diabetes, via a support group, but she is apprehensive about how they would react and whether or not they would accuse her of not minding her own business. She admits that in order to maintain her own decision to control her diabetes, she had to dig down deep to the bottom of her heart: "That's where the strength comes from."

Women react differently when they are diagnosed with diabetes. And what happens next? Once you are diagnosed as being diabetic, does that mean that life is over? No. Life must go on. But it will never be the same again.

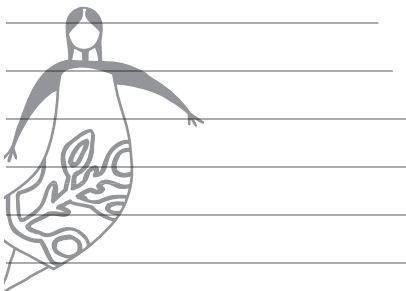


From solitude to sharing

- 4. Did you experience solitude or rejection?
- 5. Did you get support from your family?



- 6. Are you able to set your limits with regard to others?



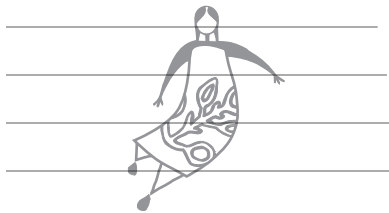
Often, the most sudden change that diabetes brings to a woman's life is solitude. Having been accustomed to her status as a full-fledged member of the family and the community, she now has to grapple with possible rejection and the reality of rejection by certain people. Rejection might be felt through the silent treatment she gets when she tries to express herself. It might be the rejection of her disease - her friends might encourage her to eat or drink unhealthy foods, even though they know she is trying to control her diabetes. The lack of support can be felt behind the apparent kindness of a friend's insisting that you have a piece of cake, giving you the choice either to politely accept and suffer the consequences, or to refuse and risk hurting someone you truly like and then feel that you are different from everyone else.

Many activities that are usually associated with the joy and sharing they bring to life are now called into question - the simple fact of going to the local restaurant has now become synonymous with temptation, which must be resisted. You feel like you're the only one living through this. We are even convinced that our symptoms are unique. To admit having diabetes can be all the more difficult, especially because no one talks about this sickness and because we were raised to never talk about ourselves, especially about our illnesses. We are assailed by a legion of "I can't's" and "I shouldn't's" and the isolation only increases. In a nutshell, our links to others seem to be eroding.

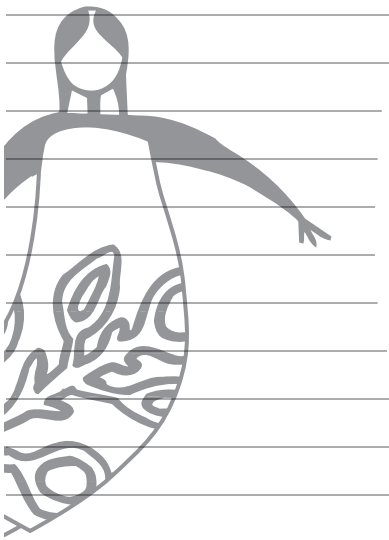




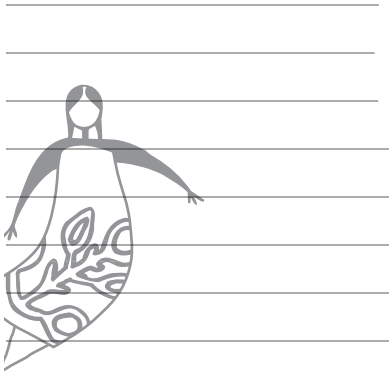
• *Nobody talks about it, not a single person.*
• *If you want to keep your secret, keep saying you're a diabetic, then the others won't say anything.*



They just gave me this prescription of pills, and when I got home, I sat in the kitchen and I said, "Oh, I'm diabetic and I have to take this medication for life, I'm going to die and bla bla bla." Everybody ran away from me.



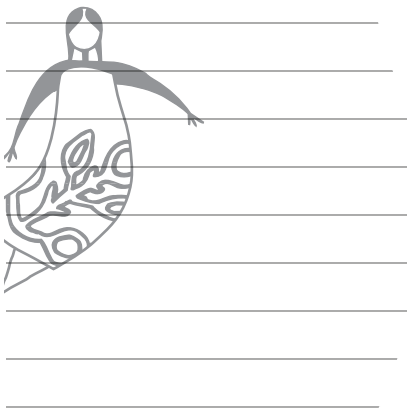
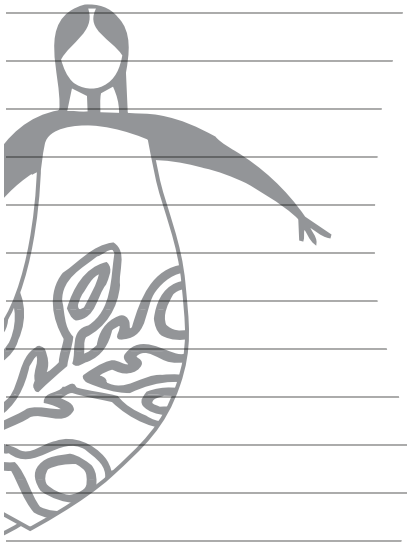
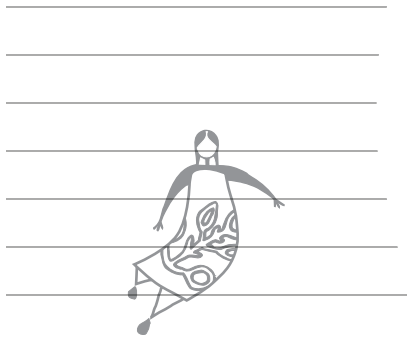
I never go out, I always stay home and I say, "Well, I'm not going because I don't have enough money." But it's not the money, it's the isolation. Like, if I go to a restaurant, I sit down and I want to eat everything. And if I do eat too much, I know my glycemia is going to get high and I don't want that. For me to avoid eating something bad, I don't go.



You have to take a piece. "Have a piece of this, have a piece of that." And I say, "No I'm not, I'm not eating everything. Don't make me anything, I don't want anything." They feel more hurt then anything, so I just... I'm not going. That's it.



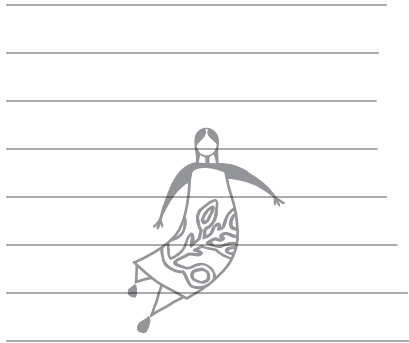
7. Is being alone a burden or a treasure to you?



Not all women are alone in their trials. A husband, a daughter, a sister, a friend or a health professional may be there to help her through the difficult moments. But there is also that painful solitude which one is forced to adopt, either because of events or other people. However, it is also in solitude that many women find solutions. Then, solitude reveals its riches and becomes a place of rebuilding and reaffirmation. And when you reach the turning point in the road, you may discover others there too, who are living the same experience and who are ready to share.



All those things we used to love doing

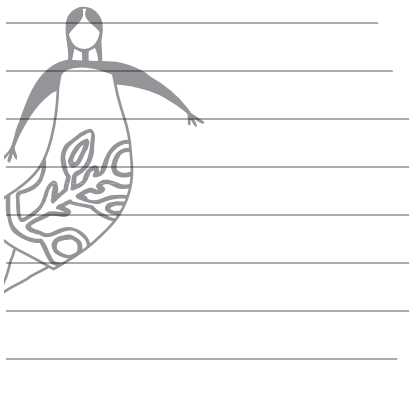


Diabetes often strikes women after they have already developed a multitude of habits and tastes for certain activities and foods. Without our knowing it, such habits and tastes were precious to us and were part of our life; they had become our life. They were the landmarks on our road, the little rewards that we gave ourselves, little kindness that we were proud to be able to do for our children and family. Perhaps we didn't notice them before, but today we idolize them.

8. Are there things that you used to enjoy but can no longer do today?



Then, diabetes sets in, and we are convinced that we will never regain our former well-being. That well-being was based on a great many details, on the thoughtless pleasure of eating cake whenever we felt like it, the ability to do our daily tasks, the pleasure in making meals for our children, accepting an invitation to eat with friends, or travelling to a neighbouring community to visit a relative, all without having to worry about taking our medication. We now have this sickness and we have to sacrifice what seemed to us be the most normal and legitimate things in life.

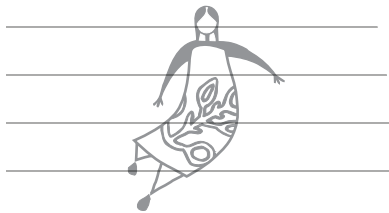


Diabetes seems to create a gulf between what we were and the things now available to us. Does it mean giving up on everything, depriving yourself of everything? At first glance, it would seem to be so. The list of things that we can no longer do and the things that we are obliged to do seems very long indeed.





If you're diabetic, one thing is certain - you can't do as many things as someone who is in top shape.



*• I always have to rest in order to be in good shape for the next day. It's not like it was before; then I had more energy.
• But do you rest now?
• Well, I want to make sure that my batteries are recharged for the next day.*

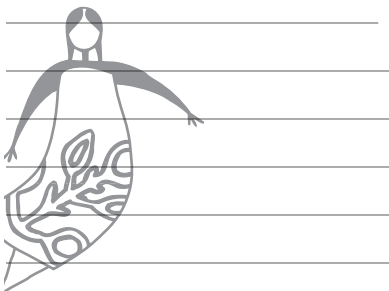
9. What kinds of food are normal and accepted in the community? (e.g. describe a normal meal)

10. Are there any foods or activities which set us apart from others or cause us to be rejected?

11. How can we introduce new foods into our lives?

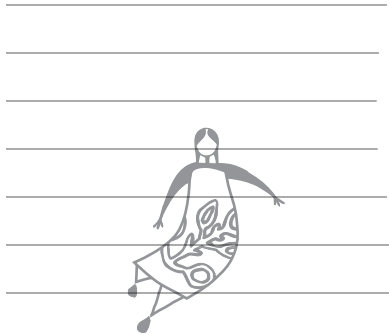


I can't stand salad. I take the lettuce out of my hamburger, I hate it so much. I will eat salad from time to time, but don't count on me to eat it four times a day. Maybe once a week, that's enough for me. But I could eat bread everyday. Bread and potatoes, that would be enough for me. Or molasses. Some times I'd like to have something fatty, with home-made bread and then some sugar, brown sugar. There are lots of things that we always had at home when we were young, which we can no longer eat.

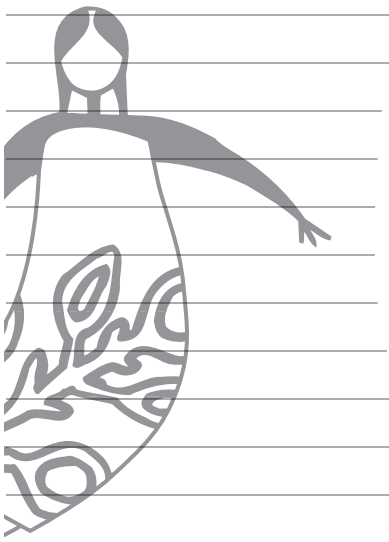


The hardest thing is the diet. Medication is nothing compared to that. When you're used to being able to eat anything at all, and then all of a sudden you have to start cutting things out, that's serious. You have to start watching what you eat and checking to make sure there's no fat, no...



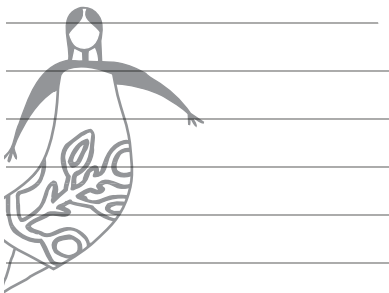


Some times, I think that I would like to make fudge. But I know that if I do, I will likely binge. I no longer make certain things, because I know that I will devour them. Then there are the deserts that I no longer make at home because I will binge. I hardly do any cooking now, aside from my bread.



You have to cut out so many things. You have to give up the things you like the most. In fact that's exactly what I did. Whatever I liked the best, I gave it up, and I settled for the things I liked the least.

Instead of thinking in terms of enduring changes, we make a list of all the things of which we have deprived ourselves. But women who have got their diabetes under control learned that the things they first considered to be banished forever were still accessible, as long as they made the effort to use them more moderately or to organize their lives differently. It is still possible to spoil our family, without having always to treat them to sweets and to be our same self with others, only in a different way, one that doesn't deny our new reality. It is even possible to begin to look at the changes we have to make to your diet as a kind of health revolution for the family. As one women put it, we would never want our loved ones to develop diabetes. The new behaviours we adopt become, in a certain way, examples for prevention which might be passed on to future generations.



I said, "Well, I want to go to Maine, can I go to Maine? I have to bring my insulin." You're trained to put that insulin in a fridge. Now, when I go far I will say, "I need to take a refrigerator for my insulin,"



Four horizontal lines for writing.



And it's not easy... all these constant reminders that you have diabetes. But the people you love and care for a lot, you don't want them to have what you have. You like to do some prevention, for them and for the next generation.

12. I like each of us to tell the story of a small or a big victory over herself.

13. What is our reaction when we stumble?

Large illustration of a person in a patterned apron, with horizontal lines for writing.

It seems that adopting so many changes will not be easy, and that from time to time, we will stumble on our path. But at such times, it is worthwhile to evaluate the progress we've made and to let ourselves take heart from our small victories. We must recognize that we are not perfect, but that our journey is unique and is part of the love that we must have for ourselves in order to rid ourselves of the burden of guilt and continue to move forward. A little effort goes a long way. Our greatest victories will be the ones that we win over ourselves.



There are days that I don't want to cope with this disease. I have a hard time. But I have noticed that I am accepting it a little bit more now and I'm trying to follow my diet. But I slip every once in a while.

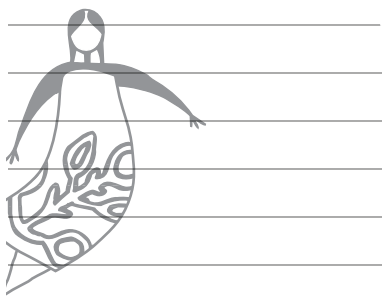
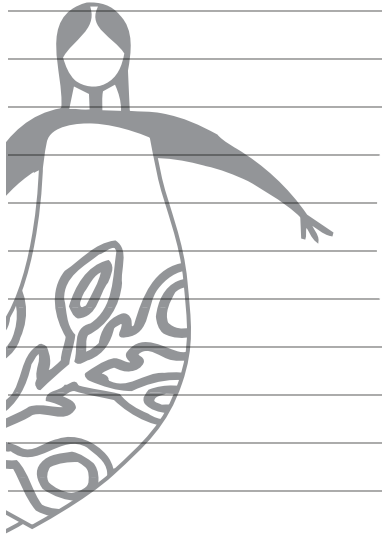
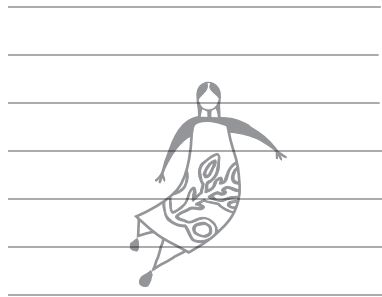
Large illustration of a person in a patterned apron, with horizontal lines for writing.



I was eating a lot, now I don't. I have changed my eating habits. I'll just eat a little bit. And I watch what I drink. Sometimes I slip but I put myself back on track.. And what else do I do? I exercise.



14. Do some things seem less important now than they did in the past?



The things that we used to consider as important, that we found so painful to give up, may even become trivial with the passage of time. Both life and time help to smooth over many difficulties.

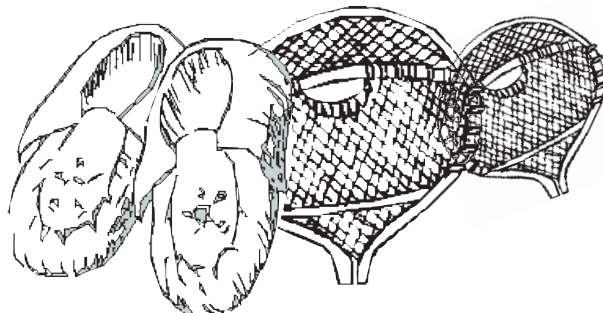


• You used to like to cook?
• *Oh yeah ! Once in a while I cook. Last week I cooked for the community. But... food is no longer important. And I'm glad that it's not important to me anymore.*

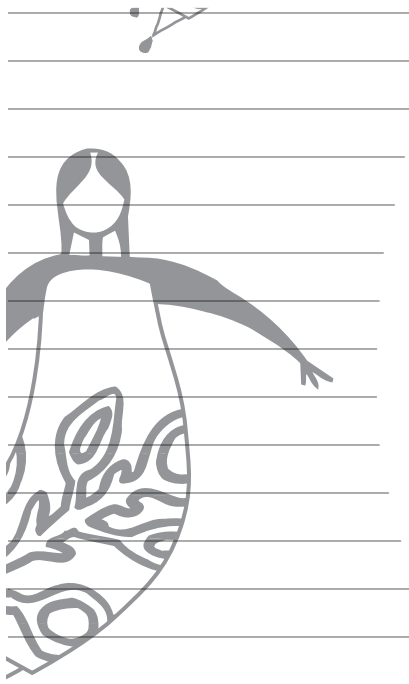
There are many others who suffer from some form of chronic disease. The ways that they cope with their troubles may be a source of inspiration for us. Do these people have a secret?



My mother, she's so stubborn. She's coping with it. Well, there are days that she has bad days and there are days that she's okay and does the same things she's always been doing. That doesn't happen all the time, but it doesn't bother her too much. She goes to bingo every night. If there's a bingo during the day, she plays bingo during the day. I come from a very stubborn family. We're stubborn, nothing stops us! We cope and then we just say: "Oh !" You hit up against something and then you pick yourself up and go on.



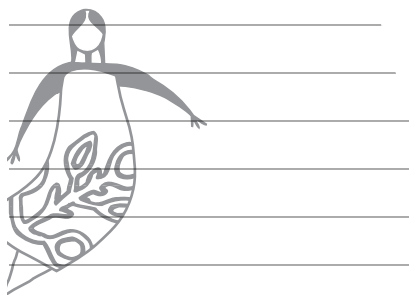
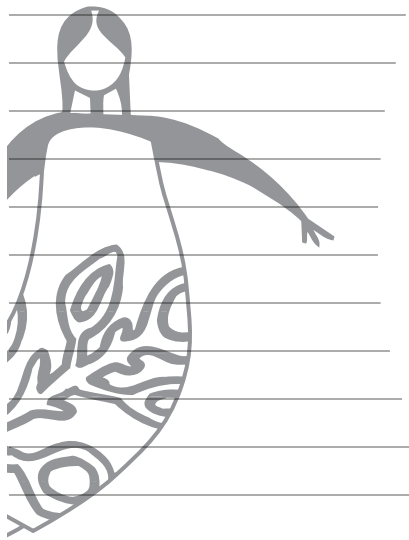
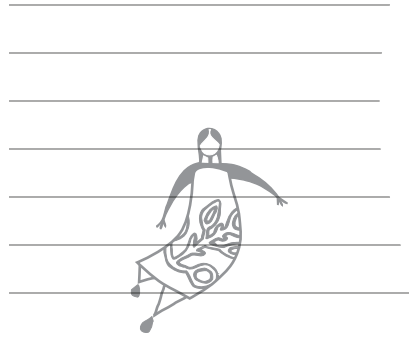
- 15. What is happiness?
Little daily pleasures?
- 16. What can destroy our happiness?
What can destroy the happiness
of our family?
- 17. What is our role in promoting the
happiness of our family?



These women don't seem to let it bother them more than is necessary; they do the same things we used to see them doing, although not as frequently or intensely. We admire them for the way they can put up with having good days and bad days, without letting that destroy them. They manage to do the things they enjoy, and maybe that is what gives them the strength to keep themselves going on the bad days. Pleasure and happiness are the two motors of life. Diabetes may force us to be content with simple joys, in a different way, and it may even lead us to discover new ones, to open our minds to something new, to retreat deeply enough within ourselves to discover our potential for happiness in all its forms. Above all, it may teach us to cultivate our own happiness, even though we have been long conditioned always to think first about the comfort of others.



Do what you love or love what you do?



We know what's good for us, we've had it repeated to us often enough, we've read enough about it or seen it often enough on television. But that doesn't mean we love it. Is that which is good for us automatically something we don't like to do? The same thing goes for having to give everything that we enjoyed before diabetes- we don't like it. But loving something can be the result of a decision, the decision to enjoy it, the decision to keep an open mind about it and to derive some benefit from it. You don't enjoy walking alone in the street any more than a fly is attracted by vinegar. Do you have any ideas about how to make it more pleasant? You might, for example, go for a walk with others and then play a game of cards together...



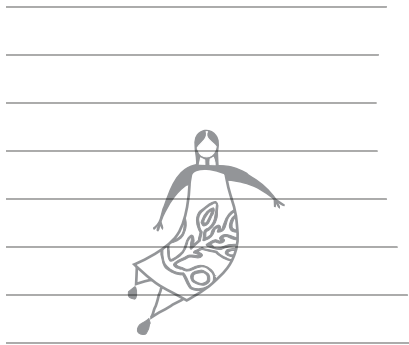
- What would be good for you?
- *Going for walks, for example. Any activity, going out on snowshoes or doing other activities that I enjoy.*

And what does it matter if diabetes becomes an excuse for your behaviour? Do things you always enjoyed, this time because they are good for you. Tell your family that you are the only one who will work in the garden because you need the exercise. Listen to music, do whatever gives you back your strength. It's up to you to get rid of your complexes if you want to face the opinions of other people without being ashamed.



Anything that you like doing, you're going get it done. Something that you don't like doing, you're not going to put your full effort into it because you don't care. But you have to like what you do in order to get it done right. Imagine, the music brings me alive. And there's something about music, you know. I said, "I wish I had a camera to take my picture, how ugly my dancing is." But I don't care, as long as I'm moving.





I don't want anybody else to touch my garden. I want to do it myself. And I go out after work, I just go out in my garden. And I stay there until... I even forget to eat sometimes. Because I'm out there busy digging flowers, or growing flowers or whatever. Fixing my trees, cutting the grass... And the front is my area and my husband is not allowed to come with that lawn tractor. It's where all my trees and flowers are. He asks me, "Why?" I say, "Because I want to exercise !"

18. Are there any activities which help us to forget or make us happy?

What makes these activities so enjoyable?

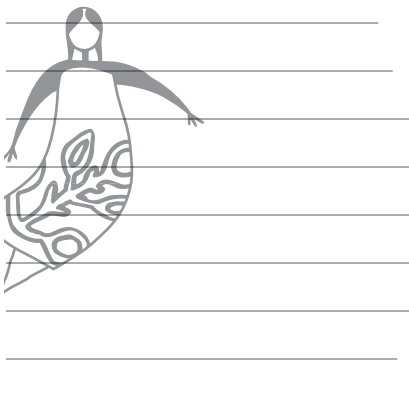


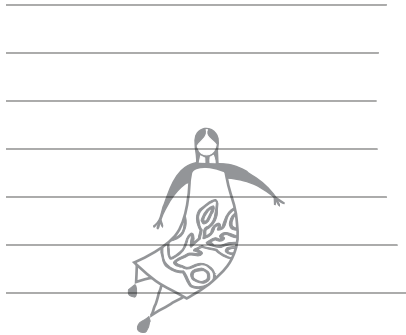
Some activities can help us forget everything, because they are so intense and vital. They can become almost like a vacation or a holiday that takes you away from your diabetes. As this diabetic woman said...



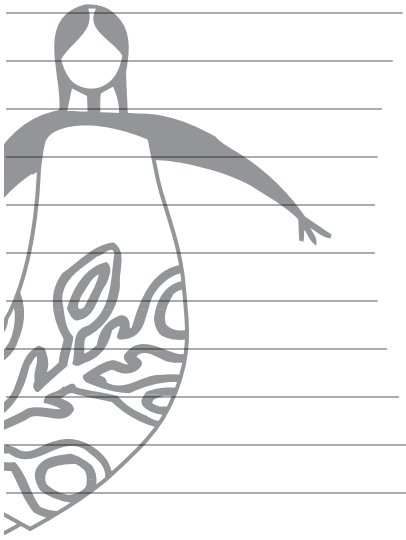
In the woods, I never think about my sickness. When I'm in the community, it's almost as if I were more ill. But when I'm in the forest, I feel so good that I don't feel anything.

Many women are more successful at controlling their diabetes in the woods, far away from the stress of the community. In nature, they can eat the food they enjoy, listen to their needs, feel free of their burden. This is a release-valve activity, a chance to let off steam and to set off again on the right foot. Why not take full advantage of the opportunities you have to do such things? Why not make this kind of activity an anchor of your routine so that it becomes beneficial to your life? Then, exercise will be a joy and food, a feast.

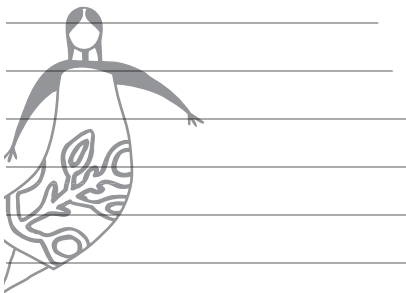




I'm a woman who likes the woods. Every weekend after work, I go out to the woods. During the holidays, when I've got time off, I always go to my camp. There I do everything on foot. I don't have a sleigh or a snowmobile. The only thing I have is an all-terrain vehicle to get there. But everything else, like putting out snares and traps, is done on foot.

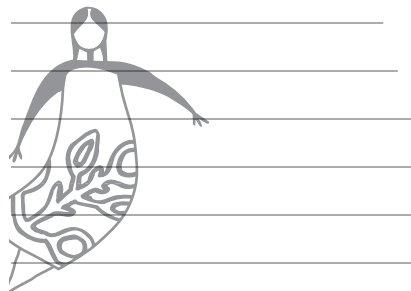
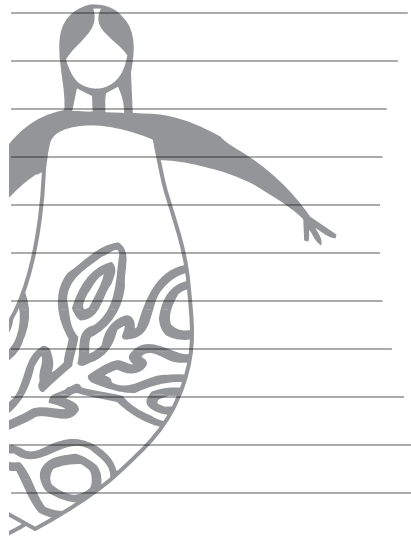
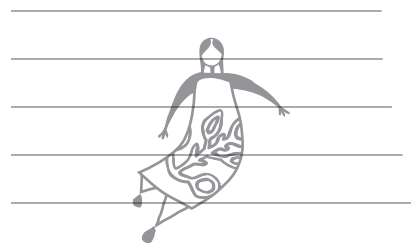


When I go into the woods, I have a lot less stress. And I really enjoy game meat. When you're in the woods, in nature, you don't have nearly as much stress.



Talk about yourself - and be yourself - even when you're with others

19. Who should we tell we are diabetic? Why?



Diabetes introduces a new factor into our relationships with others, at many different levels, with regard to what we say and what we do not say, for instance. Is it better to announce it to everyone that you're diabetic? Is it better to keep it to yourself? Tell the whole family, but remain silent about it in public? There are as many answers to these questions as there are diabetic women. However, it is a good idea to ask yourself why you decide to announce or why you want to keep it private. It is quite possible that we don't want people to pity us and that we are ashamed of being diabetic. We don't want special treatment. In the end, we're afraid of being marginalized in the community.

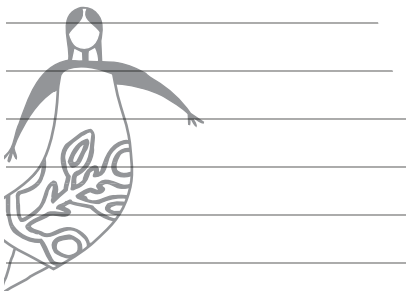
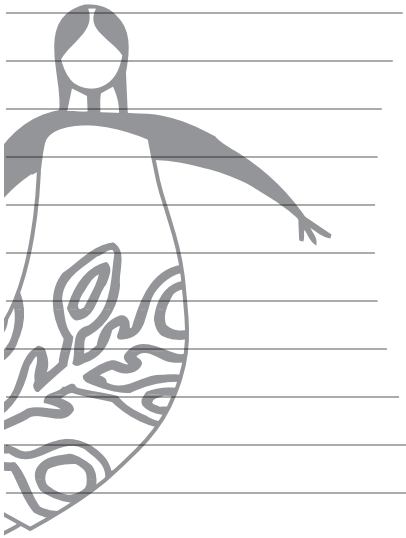
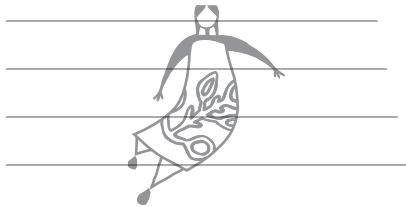


- Do you tell everybody you're diabetic?
- No.
- *Me neither, I can't. I don't want them feeling sorry for me.*
- *I do. I tell them if they ask. I'm diabetic. So they'll know and... if I get sick somewhere, they'll know what to do. But I'm not wearing a bracelet or anything.*
- Why don't you tell people?
- *I don't know. I don't... I don't want them feeling sorry for me. "Oh, she's diabetic." You know, I don't want anybody to tell me, "Oh, you're sick, you have to do this, you have to do that."*

On the other hand, are we ready to announce without embarrassment to one and all that we are diabetic? When we act in this way, it is often out of bravado or self-derision, to show that we don't take ourselves too seriously. For example, you're out walking in the rain and you try to make your friends laugh by telling them you have the sugar illness and you're going to melt away in the downpour. You use dark humour as you swallow a piece of cake. Humour may be a way of asserting yourself before others or of getting their support.



- 20. How can a diabetic break out of her isolation?
- 21. Is being different acceptable in our community?
- 22. What do you do to find support?



The solitude that a diabetic woman lives is a way of withdrawing into herself with her problem. But by saying nothing, you will never get any support. And if you tell others everything, you leave yourself open and vulnerable; doing so will likely provoke comments, not all favourable, and much of which are mere gossip. How can women just simply announce, and announce to the right people, that they are diabetic? What strategies can they use to do this?



I think, "Now I've got it". It won't go away, I've had it for years, but I will tell my friends about it, in case I get sick. At least the people in my immediate circle know that they can do something to help me.



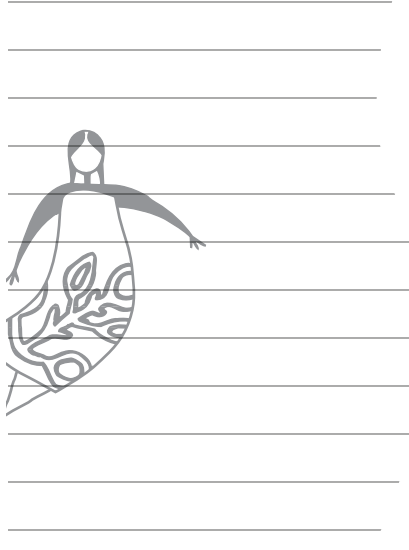
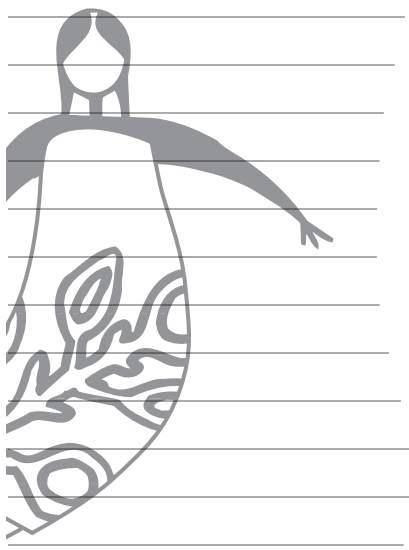
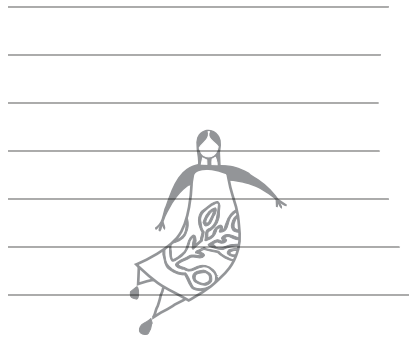
There are people who support us indirectly. I support a friend sometimes and I tell him, "There's something at the store that would be good for you." Then I go pick it up for him. But that is indirect support. I see something and I say to myself, "This will be good for him." I tell him about it. He might already have it or he may never have seen it. It's still a type of support. Sometimes people will encourage us. They say, "Good Lord, I didn't even know you were diabetic. It doesn't show. You do so many things." I reply, "When we're diabetic, we can still have good health.."



When things aren't going well, I tell the nurses about it. Or I tell some of my close friends whom I trust. They might talk to me about their feelings, and then I will talk to them about my problems our my health. I can trust them to keep it confidential, just as if I was talking to my husband or to my children.



23. Do you have a private life?
What things are included in it?



We talk to people who are likely to be able to help us, or we might be more open with colleagues at work, and thus create for ourselves the opportunity of getting help in unexpected ways. On the other hand, we might decide to talk about what is happening to us only with people who we can trust and who share things in common with us. In this way we can be sure that our private life will be respected and kept confidential. Because diabetes has created new concerns for us and generated new desires to find support, we find a certain degree of comfort in the fact that we are able to educate our family as to how they can best help us if the need arises. Other people don't change just because they've learned that we are diabetic. They might not have an inkling as to what we need.



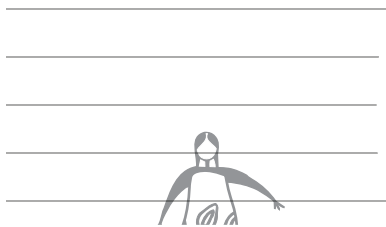
But sugar diabetes is something we need to be taught about. It needs to be passed down from one generation to the other. And you have to tell your neighbours about your health, let them know. All my kids, if I ever get sick, they know how much insulin to give me because I taught all of them. I brought my machine, I brought my needles and I taught them how to do. I told them, "Sometime, I won't be able to help myself."



- Then for you, just by talking about it to your family is a type of support?
- Yes, because you know if you've told enough people, there's bound to be at least one who will be able to help you. If you fall, the others will know what's wrong and will be able to help.

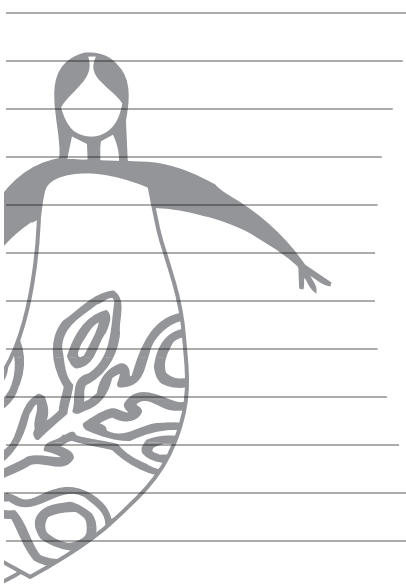
It's important, of course, to maintain the privacy of our lives, but we may also want to teach others what we've learned over the years and thus help to prevent diabetes in future generations.





I think the reason why I never talked about it is because I didn't have any knowledge of it. I didn't know too much about it. I knew I was diabetic, but that's about all. And you don't talk about something that you don't know about. Now, I could talk about it, I know quite a bit about it.

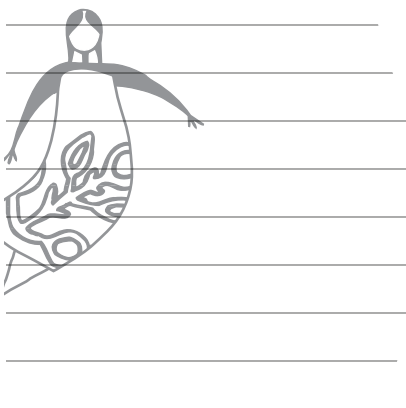
24. Does it help sometimes to talk about your situation?



Sometimes, when we come out of the isolation that we had chosen for fear of being judged, we notice that it does us good to talk with people who have experienced the same things. Knowing that we're not alone is a comfort that we might not want to give up. It leads us to seek out more occasions to discuss our experience with others who are struggling against the same difficulties. They often give us not only some good advice, but also a sympathetic ear.

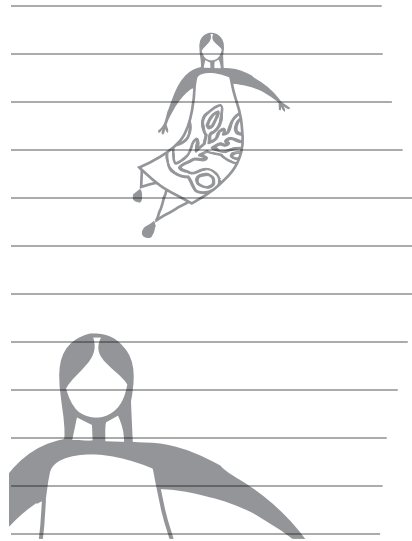


- *If they didn't call me and tell me to come to the group, I wouldn't have come, because I don't want to talk about it.*
- *Why don't you want to talk about it?*
- *I don't know.... I say, it's my disease, I can control it. I don't need anybody else. That's the way I feel about it.*
- *And now, do you feel that you've enjoyed talking about it?*
- *Yeah. I enjoyed it after I started talking about it. And we shared what's happening to each one of us...*
- *Because it's not just you.*
- *Yeah, it's not just me...*
- *There are other people who are diabetic.*
- *We're not alone, we're not alone.*



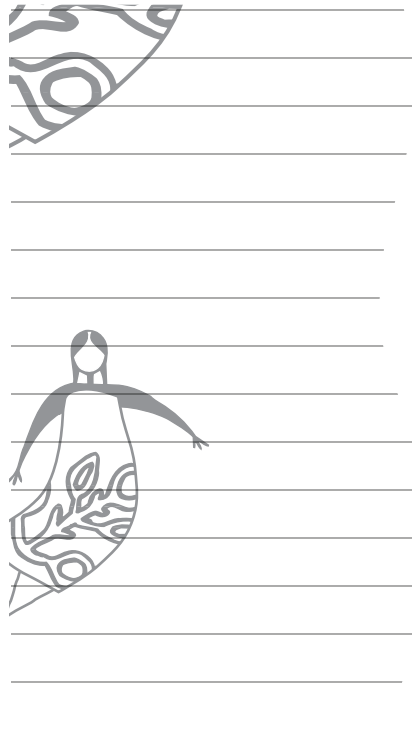
Seeing things differently

25. What is our role regarding people in the community who do not have diabetes?



When we are diabetic, our eating and drinking habits must change, our sleeping hours are no longer the same, we have to be more active and listen to our bodies. And we especially have to change our actions. But it might be just as painful to watch what others are eating, since we know it is not good for their health. A pleasure as simple having a bag of chips in front of the TV can be worrisome if the person enjoying this ordinary pleasure is someone we love, and whose health we care about. In short, to our minds, nothing is the same any more. We no longer feel comfortable when we see others indulging in habits which led to diabetes in us. This is another factor that can isolate us from others, even leading to a certain degree of rebellion.

26. How can we help prevent new cases of diabetes in the community?

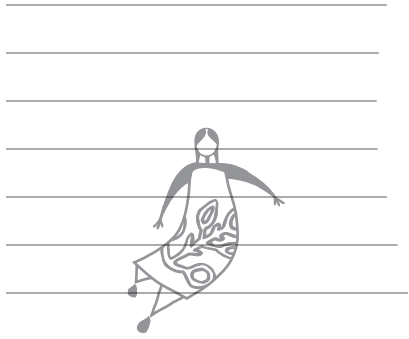


Why not channel this rebellion into concrete actions which will help change the situation?

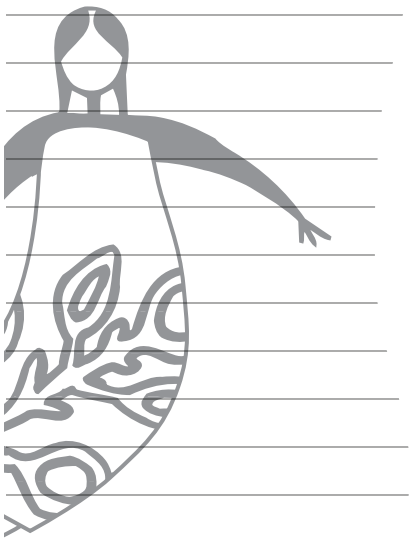


Ever since I learned what diabetes is, I know longer like watching my family eat chips every night, instead of cooking a healthy fat-free meal. I can't believe it when I see people eating like that. I know that sometimes I like to indulge in a good desert, but not every day. The same thing goes for sweets and chocolates. I try to teach my children to drink diet pop, which has much less sugar. At first I never said anything about them having chips, but now we try to eat less chips, less chocolate... I can't get over it when I see people eating like that.





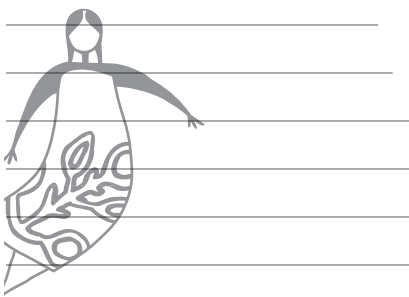
In any case, I always think, there's still hope for the children. I just have to think back to when I lived with my own mother and about what we used to drink: Kool-Aid, Tang. Coloured crystals basically. When I got my own home, my children asked for Kool-Aid and Tang and I told them no. I buy frozen juice, I don't buy coloured crystals. Now try to get my son or my daughter to drink Kool-Aid. The grimace saying "Ugh, sugar!" They don't want it.



Perhaps we don't have the time and energy to help others as we did in the past. However, the knowledge and habits you acquire by thinking about your own good may be more beneficial to others than you suspect, and may also create stronger and more healthy relationships and a greater sense of sharing with loved ones.



I tell women who are depressed, Go take care of yourselves. Go out, get some rest, take a bath, and eat if you want to. You can clean up your room, change the sheets. You'll see what a difference it makes. Do something. Then you'll see that when you need something, sometimes it's because you don't know how to ask. Talk to your husband about it; tell him, "I would like to be caressed in this way."



I go for a walk every evening with my husband and with my daughter who is diabetic. I ask her to come on the walk with us. Now she's the one who wants to go for a walk.



Suggested questions for facilitators

1. Why is there diabetes?
2. Did you change anything in your life after learning that you had diabetes?
3. Did you accept being diabetic immediately?
4. Did you experience solitude or rejection?
5. Did you get support from your family?
6. Are you able to set your limits with regard to others?
7. Is being alone a burden or a treasure to you?
8. Are there things that you used to enjoy but can no longer do today?
9. What kinds of food are normal and accepted in the community? (e.g. describe a normal meal)
10. Are there any foods or activities which set us apart from others or cause us to be rejected?
11. How can we introduce new foods into our lives?
12. I'd like each of us to tell the story of a small or a big victory over herself.
13. What is our reaction when we stumble?
14. Do some things seem less important now than they did in the past?
15. What is happiness? Little daily pleasures?
16. What can destroy our happiness? What can destroy the happiness of our family?
17. What is our role in promoting the happiness of our family?
18. Are there any activities which help us to forget or make us happy? What makes these activities so enjoyable?
19. Who should we tell we are diabetic? Why?
20. How can a diabetic break out of her isolation?
21. Is being different acceptable in our community?
22. What do you do to find support?
23. Do you have a private life? What things are included in it?
24. Does it help sometimes to talk about your situation?
25. What is our role regarding people in the community who do not have diabetes?
26. How can we help prevent new cases of diabetes in the community?





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