

In the Loop

Adolescence, sexuality and chronic illness

Part 1

Can you remember your first sexual experience? Not necessarily the first time you had sex, but your first experience of sexual intimacy. Maybe it was behind the bike shed and the culmination of a serious crush. Or perhaps you kissed the girl or boy left over after your friends paired up. Maybe it was a magnificent moment of mutual lust. Or a horrible exchange of saliva and you wished you had said no. Chances are that the memory makes you blush, laugh, squirm or grimace. Chances are you were taking one of your first steps in exploring your sexual identity, making sense of who you are as a sexual human being. Chances are you may never have spoken with anyone about how it was for you. Chances are that you were a teenager.

There is so much that happens in adolescence, and exploring our sexual identity is only one part of the action. Sexual identity emerges alongside the physical changes of puberty, the advances in thinking that allow for abstract thought, the transition from dependent child to independent young adult and the decision-making shaping further education and a career. All of that is tumultuous enough when you are physically well, but what is it like with a chronic illness or disability?

A chronic illness or disability throws up additional challenges; chronic illness impacts on a person's sense of themselves and on how they are perceived by others. The illness may be genetic and able to be passed on. The act of sex or carrying a pregnancy may pose medical risks. Parents of a young person in this situation may feel very protective due to the illness and may limit their teenager's opportunity for important social interactions.

Professor Susan Sawyer is a specialist in adolescent medicine who works with young people with chronic illnesses. She thinks the issues facing all adolescents are tough, let alone young people with health issues. "The change in thinking in adolescence gives the young person a much more refined ability to compare and contrast. So at the very time that their bodies are changing so dramatically, they are very tuned in to difference. They develop the ability to look at themselves and compare themselves with their notion of the perfect body. Adolescence is also very much about imagining an ideal world, whether it applies to politics, environmental issues, or the body beautiful. Most adolescents have a very narrow

perspective of what is beautiful and most find that they do not measure up.

"While young people develop these new cognitive skills of comparing difference and idealism, they usually lack the more mature thinking that says, 'It is not just me who is different; we're all probably average and okay and good enough.'" For most of us, that comes later, which means that there is a period when many young people give themselves a hard time about their appearance, believing that they are the only ones who are not beautiful.

What does all of this mean for parents of young people with chronic illness or disability? "The central questions for young people with chronic illness or disability in adolescence are no different from those of anyone else. They want to know:

Who am I?

What am I going to do with my life?

Is anyone going to love me?

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A WORLD OF DIFFERENCE: BECOME A LIVING DONOR & WORK FOR THE LUPUS ASSOCIATION FOR 1 YEAR

The Vodafone Australia Foundation is looking for Living Donors to take part in the 2009 World of Difference Program. While you donate all of yourself to the charity of your choice for a year, Vodafone will pay you a salary of up to \$50,000 and cover \$25,000 in related expenses.

Applications open Thursday 1 January and close at 6pm EDST on Friday 6 February 2009. To apply, go to <http://www.vodafone.com.au/personal/aboutvodafone/worldofdifference/index.htm> and complete the form online.

YAHOO! young adults email group for lupus and Sjogrens

To become a Yahoo! Young Adults Email Group member, go to: http://health.groups.yahoo.com/group/lupus_youngadults/

For assistance on how to become a member of the group, email Kelly on kelbret@onthenet.com.au.

If you prefer, the Lupus Association can also help to put you in direct contact with other members in your age group or your area (where possible). Just ring or email the office.

FRESH FRUIT SALAD WITH HONEY-YOGHURT DRESSING

This is a simple and healthy summer snack that is good for you AND absolutely delicious! The recipe below serves 6 but is easy to adjust as required.

Ingredients: • 1 cup vanilla yoghurt
• 2 tablespoons honey • 1/2 teaspoon ground cinnamon • 2 oranges, peeled, sliced and cubed • 1/2 large pineapple, peeled, cored, sliced and cut into wedges • 1 apple, cored and chopped • 1 pear, cored and sliced into wedges • 1 kiwi fruit, peeled and sliced. You can also substitute your favourite fruits...

Method: • In a small bowl, combine the yoghurt, honey and cinnamon. Stir well to blend ingredients. • Arrange fruit on plates and drizzle with honey-yoghurt dressing.

make your contribution

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So it is really important that parents of young people with the added burden of chronic illness or disability have high expectations around what their teenager is going to do with their lives; that they will get a job, contribute, end up in a happy relationship, get married, and if they want to have kids, find ways that children are meaningful in their lives, even if they can't biologically do it. So if a teenager is in a wheelchair, it is important that parents expect that this young person will have a partner - why wouldn't they?"

This might be a shift in thinking for some parents who continue to view their teenager as a child. Illness in their child often brings out the protective instinct in parents, and mostly this is a good thing. "The challenge for parents as their child moves into adolescence is to appreciate that their child is now a teenager, chronic illness or not. And all adolescents learn by doing, by experimenting, by succeeding and having the confidence to succeed, but also by making mistakes and learning to do things differently the next time. I encourage parents to think of their adolescent first and foremost as a teenager, who happens to have [for example] diabetes. If parents think that denying that their son or daughter is a teenager will help manage their diabetes, it will come back to bite them big time."

With illnesses such as diabetes, many parents feel worried about letting their child stay at a friend's house, or go on camp, where the parent cannot help monitor their blood sugar and insulin requirements. Professor Sawyers encourages parents to find ways for their teenager to be part of these activities whenever possible. "School camps are really important bonding opportunities, a chance to develop social relationships, and this is such an important aspect of a young person feeling okay about themselves and where they fit in a friendship group."

The problem is that the stakes are high. Allowing a teenager more independence in managing their illness might, in the short term, make their illness worse. Professor Sawyer talks with families about working towards the young person managing their own disease, knowing that this won't happen overnight. "I liken it to a dance that parents and the young person do: at one moment, the parent is leading and the young person is following, but the parent needs at times to step backwards and allow the young person to lead, and at other times to step up to the mark and provide some guidance."

• Part 2 of this article will appear in the next edition of "In the Loop". This article is reproduced with consent from the author Dr Susan White, Clinical Geneticist. It originally appeared in Sydney's Child (October 2008).

For more information about In the Loop contact Kelly Davidson on 02 6676 2646 or kelbret@onthenet.com.au or contact the Lupus Association of NSW on 02 9878 6055. If you would like to make a written contribution to In the Loop or suggest a new feature or article idea, we'd love to hear from you! You can also obtain heaps more information from the Lupus Association of NSW Inc's website : www.lupusnsw.org.au