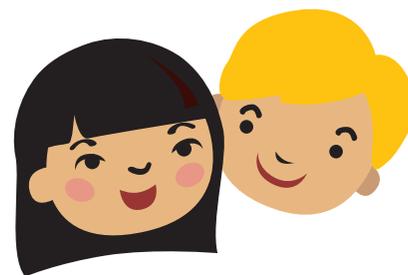


# quality of life for youth

Questions about living with diabetes



The following questions are about how you see your life with diabetes. Circle the number that gives the best answer for you. Please provide an answer for each question. Please bring the completed form with you to the next consultation where it will form the basis for a dialogue about how you are coping with your diabetes.

Patient name:

Completion date:

Interview date:

	Newer	Very seldom	Some times	Often	All the time	Total score 0-12
<b>Impact of symptoms relating to diabetes</b>						
<i>How often do you...</i>						
1. Feel physically ill?	0	1	2	3	4	
2. Have a bad night's sleep?	0	1	2	3	4	
3. Miss school because of your diabetes?	0	1	2	3	4	
<b>Impact of treatment</b>						0-12
<i>How often...</i>						
4. Do you feel pain associated with the treatment?	0	1	2	3	4	
5. Does diabetes interfere with your family life?	0	1	2	3	4	
6. Do you feel restricted by your diet?	0	1	2	3	4	
<b>Impact on activities</b>						0-20
<i>How often does diabetes...</i>						
7. Limit your social relationships and friendships?	0	1	2	3	4	
8. Prevent you from bicycling or using a machine (e.g. a computer)?	0	1	2	3	4	
9. Interfere with you exercising?	0	1	2	3	4	
10. Interrupt your leisure time activities?	0	1	2	3	4	
11. Prevent you from doing activities at school?	0	1	2	3	4	
<b>Parent issues</b>						0-12
<i>How often do you feel that your parents...</i>						
12. Are too protective of you?	0	1	2	3	4	
13. Worry too much about your diabetes?	0	1	2	3	4	
14. Act like diabetes is their disease, not yours?	0	1	2	3	4	
<b>Worries about diabetes</b>						0-28
<i>How often do you worry about whether...</i>						
15. You will get married?	0	1	2	3	4	
16. You will have children?	0	1	2	3	4	
17. You will not get a job you like?	0	1	2	3	4	
18. You will faint or pass out?	0	1	2	3	4	
19. You will be able to complete your education?	0	1	2	3	4	
20. Your body looks different because of diabetes?	0	1	2	3	4	
21. You will get complications?	0	1	2	3	4	
<b>Health perception</b>						0-4
22. Compared with others your age, would you say your health is?	Excellent 1	Good 2	Fair 3	Poor 4		

DQOLY-SF © 2006: H. Hoey, H. M. McGee, T. C. Skinner and S. E. Skovlund

# quality of life for youth

## Questions about living with diabetes

### The “quality of life for youth” questionnaire

The achievement of good metabolic control is difficult in children, and particularly in adolescents. Having diabetes requires a complex, intrusive and highly demanding daily programme for families, which may have a negative effect on Quality of Life (QOL). Good Quality of Life is associated with better metabolic control.

### Why use the “quality of life for youth” questionnaire?

It is vital that clinicians are able to assess QOL and identify issues which may affect it, particularly as these issues may not be obvious during the clinical consultation. The “quality of life for youth” questionnaire is a valid assessment that enables the identification of specific issues which are negatively affecting QOL. It provides an opportunity for enhanced communication between the patient, family and diabetes care team, and also an opportunity to resolve these negative issues.

### How to use the “quality of life for youth” questionnaire

The questionnaire can be used as part of any routine diabetes consultation. The young person can be asked to complete the form at home or in the waiting room prior to the consultation. The completed form should be reviewed in the consultation by the nurse, diabetologist or psychologist, together with the child/adolescent. It can be used to identify issues that may be interfering with daily diabetes management and quality of life and can help prompt a dialogue about issues of particular concern for the young person with diabetes. The questionnaire can be used to obtain a reliable quality of life score that can be used to monitor changes over time and individual response to changes in therapy.

To further enhance the focus on the young person’s own agenda, an additional question can be added at the end of the form as follows: “Which topic would you most like to discuss with your diabetes care team today? (e.g. treatment related issues, school, home, sport or other areas)”. This question is not to be scored but can help facilitate dialogue.

### What is the “quality of life for youth” questionnaire?

The “quality of life for youth” questionnaire was developed from the revised 52 item DCCT Diabetes QOL for Youth Questionnaire (\*1). This shorter form is a more precise version with improved construct validity and with items known to be associated with metabolic control. It has been validated for children and adolescents aged 10-18 years and has been translated into 16 languages to date (\*2). The questionnaire is quick and easy to score and allows comparisons across countries and cultures.

### Scoring of the questionnaire

Each item has five possible scores with a value from 0 to 4, with 0 representing ‘never’ and 4 ‘all the time’. Higher scores indicate a more negative impact of diabetes and poorer QOL, and lower scores indicate greater QOL. The scoring of each subscale is done separately by summation of scores for each item within the subscale. Emphasis on a score for each subscale, as opposed to a total score, puts a greater emphasis on each item and subscale and thus highlights a problem in a single area.

For ongoing monitoring and comparison to normative scores, standardised scores with a range from 0-100 can be calculated as follows:

Total QOL Impact score:  $100 * (\text{raw total score} - 21) / 84$

- Impact of symptoms:  $100 * (\text{raw score} - 3) / 12$
- Impact of treatment:  $100 * (\text{raw score} - 3) / 12$
- Impact of activities:  $100 * (\text{raw score} - 7) / 28$
- Parent issues:  $100 * (\text{raw score} - 3) / 12$
- Worries about diabetes:  $100 * (\text{raw score} - 5) / 20$
- The self-rated health perception question is treated separately and standardised to 1-100 as follows:  $\text{Score} = 100 * (\text{raw score} - 1) / 3$

A high score indicates a high negative impact on QOL.

### Questionnaire availability

The questionnaire is available in many languages from the Hvidøre Study Group on Childhood Diabetes (\*2). Please contact questionnaire administrator Mette Bauditz, Corporate Responsibility, Novo Nordisk, to obtain a user agreement form for research purposes and further information. E-mail: [mttb@novonordisk.com](mailto:mttb@novonordisk.com).

Further information about the Hvidøre Study Group on Childhood Diabetes: [hvidoregroup.org](http://hvidoregroup.org)

*The quality of life for youth questionnaire was developed with the Hvidøre Study Group on Childhood Diabetes. The questionnaire is now being used to implement evaluation of QOL in diabetes treatment as part of DAWN Youth, a global Novo Nordisk initiative in partnership with the International Diabetes Federation (IDF) and the International Society for Paediatric and Adolescent Diabetes (ISPAD).*

*The DAWN Youth initiative seeks to improve psychosocial support for young people with diabetes and their families through promotion of evidence-based tools and strategies for paediatric psychosocial diabetes management.*

For more information, please access [dawn youth.com](http://dawn youth.com)

\*1) Reference: Skinner, T. C., Hoey, H., McGee, H. M., Skovlund, S. E.: A short form of the quality of life for youth questionnaire: exploratory and confirmatory analysis in a sample of 2,077 young people with type 1 diabetes mellitus. *Diabetologia*, Vol. 49, pp. 621-628, 2006.

\*2) Copies of the questionnaire are available in the following languages: Danish, Dutch, English (North American and UK), Finnish, French, German, Italian, Japanese, Macedonian, Norwegian, Portuguese, Spanish and Swedish.