

Combined Immunosuppression and Radiotherapy in Thyroid Eye Disease (CIRTED)

Health Related Quality of Life

Dear Participant,

Thank you for agreeing to complete the following questionnaire as part of the CIRTED trial; your views are very valuable to us.

These questionnaires are designed to examine your personal views regarding your quality of life, health and other areas. You can be assured that your responses to the questions within this pack will remain confidential and your anonymity safeguarded.

Please check that you have answered all the questions before returning the questionnaires to the Researcher.

Many thanks for your cooperation.

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Section A: Quality of Life

Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response. Please keep in mind your standards, hopes, pleasures and concerns.

We ask that you think about your life in the last two weeks and circle the number on the scale for each question that gives the best answer for you as it relates to your thyroid eye disease.

	Very Poor	Poor	Neither poor nor good	Good	Very good
A1. How would you rate your quality of life?	1	2	3	4	5
A2. How satisfied are you with your health?	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied

The following questions ask about how much you have experienced things in the last two weeks.

	Not at all	A little	A moderate amount	Very much	An extreme amount
A3. How much do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
A4. How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
A5. How much do you enjoy life?	1	2	3	4	5
A6. To what extent do you feel life to be meaningful?	1	2	3	4	5
A7. How well are you able to concentrate?	Not at all	A little	A moderate amount	Very much	Extremely
A8. How safe do you feel in your daily life?	1	2	3	4	5
A9. How healthy is your physical environment (eg housing)?	1	2	3	4	5

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The following questions ask about how completely you experienced or were able to do certain things in the last two weeks.

	Not at all	A little	Moderately	Mostly	Completely
A10.					
Do you have enough energy for everyday life?	1	2	3	4	5
A11.					
Are you able to accept your bodily appearance?	1	2	3	4	5
A12.					
To what extent do you have enough money to meet your needs?	1	2	3	4	5
A13.					
How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
A14.					
To what extent do you have the opportunity for leisure activities?	1	2	3	4	5
A15.	Very Poor	Poor	Neither poor nor good	Good	Very good
How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last two weeks.

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
A16.					
How satisfied are you with your sleep?	1	2	3	4	5
A17.					
How satisfied are you with your ability to perform daily living activities?	1	2	3	4	5
A18.					
How satisfied are you with your capacity for work?	1	2	3	4	5
A19.					
How satisfied are you with yourself?	1	2	3	4	5
A20.					
How satisfied are you with your personal relationships?	1	2	3	4	5
A21.					
How satisfied are you with your sex life?	1	2	3	4	5
A22.					
How satisfied are you with the support you get from your friends?	1	2	3	4	5

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The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last two weeks.

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
A23.					
How satisfied are you with the conditions of your living place?	1	2	3	4	5
A24.					
How satisfied are you with your access to health services?	1	2	3	4	5
A25.					
How satisfied are you with your transport?	1	2	3	4	5

The following questions refer to how often you have felt or experienced certain things in the last two weeks.

	Never	Seldom	Quite Often	Very Often	Always
A26.					
How often do you have negative feelings, such as blue mood, despair, anxiety, depression?	1	2	3	4	5
A27.	Not at all	Not much	A moderate amount	Very much	An extreme amount
How fed up do you feel?	1	2	3	4	5
A28.					
How satisfied are you with your level of happiness?	1	2	3	4	5

The following two questions with a long black line require you to put a slash through the line with a pen. For example a slash marked at this point on the line would mean that you feel your thyroid eye disease is “quite noticeable” to other people but not to such an extent as “very noticeable”.

Not at all noticeable _____ / **Very noticeable**

N. How noticeable do you feel your thyroid eye disease is to other people?

Not at all noticeable _____ Very noticeable

s. How severe do you feel your thyroid eye disease is?

Not very severe _____ Extremely severe

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Section B: Appearance

The following questions are concerned with the way you feel or act. They are all simple. Please tick the answer that applies to you. If the item does not apply to you at all, please tick the N/A (Not Applicable) option. Do not spend long on any one question.

Please remember: These questions should be answered in relation to how your thyroid eye disease may or may not affect you.

B1. How confident do you feel?

Not at all Slightly Moderately Extremely

B2. How distressed do you get when you see yourself in the mirror/window?

Extremely Moderately A little Not at all distressed

B3. My self-consciousness makes me irritable at home:

N/A Never/Almost Never Sometimes Often Almost Always

B4. How hurt do you feel?

Extremely Moderately Slightly Not at all

B5. At present my self-consciousness has an adverse effect on my work:

Almost Always Often Sometimes Never/Almost Never N/A

B6. How distressed do you get when you go to the beach?

N/A Not at all A little Moderately Extremely

B7. Other people misjudge me because of my eye condition:

Almost Always Often Sometimes Never/Almost Never N/A

B8. How feminine/masculine do you feel?

Not at all Slightly Moderately Extremely

B9. I am self-conscious of my eye condition:

N/A Never/Almost Never Sometimes Often Almost Always

B10. How irritable do you feel?

Not at all Slightly Moderately Extremely

B11. I adopt certain behaviours to conceal my eye condition (e.g. wearing dark glasses):

Never/Almost Never Sometimes Often Almost Always

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B12. I avoid communal changing rooms:

Almost Always Often Sometimes Never/Almost Never N/A

B13. How distressed do you get by shopping in department stores/supermarkets?

N/A Not at all Slightly Moderately Extremely

B14. How rejected do you feel?

Not at all Slightly Moderately Extremely

B15. I avoid undressing in front of my partner:

N/A Never/Almost Never Sometimes Often Almost Always

B16. How distressed do you get while playing sports/games?

Extremely Moderately Slightly Not at all N/A

B17. I close into my shell:

Almost Always Often Sometimes Never/Almost Never

B18. How distressed are you by feeling you want to conceal your eye condition?

Extremely Moderately Slightly Not at all N/A

B19. How distressed do you get when going to social events?

N/A Not at all Moderately A fair amount Extremely

B20. How normal do you feel?

Not at all Slightly Moderately Extremely

B21. At present my self-consciousness has an adverse effect on my sex life:

Almost Always Often Sometimes Never/Almost Never N/A

B22. I avoid going out of the house:

Almost Always Often Sometimes Never/Almost Never

B23. How distressed do you get when other people make remarks about your eye condition?

N/A Not at all Moderately A fair amount Extremely

B24. I avoid going out to pubs/restaurants/clubs:

Almost Always Often Sometimes Never/Almost Never N/A

o My eye condition causes me physical pain/discomfort:

Never/Almost never Sometimes Often Almost always

o My eye condition limits my physical ability to do the things I want to do:

Almost always Often Sometimes Never/Almost never

Date _____

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Section C: Thyroid Eye Disease

The following questions deal specifically with your thyroid eye disease.

Please focus on the past week while answering these questions.

During the past week, to what extent were you limited in carrying out the following activities, because of your thyroid eye disease?

*Tick the box that matches your answer. The boxes correspond with the answers above them.
Please tick only one box for each question.*

	Yes, severely limited	Yes, a little limited	No, not at all limited
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C1. Bicycling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Never learned to ride a bike <input type="checkbox"/>
C2. Driving	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	No driver's licence <input type="checkbox"/>
C3. Moving around the house	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
C4. Walking outside	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
C5. Reading	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
C6. Watching TV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
C7. Hobby or pastime, i.e.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

	Yes, severely hindered	Yes, a little hindered	No, not at all hindered
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C8. During the past week , did you feel hindered from doing something you wanted to do because of your thyroid eye disease?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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The following questions deal with your thyroid eye disease in general

	Yes, very much so	Yes, a little	No, not at all
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c9. Do you feel that your appearance has changed because of your thyroid eye disease?

c10. Do you feel that you are stared at in the streets because of your thyroid eye disease?

c11. Do you feel that people react unpleasantly because of your thyroid eye disease?

c12. Do you feel that your thyroid eye disease has an influence on your self-confidence?

c13. Do you feel that your thyroid eye disease has an influence on making friends?

c14. Do you feel socially isolated because of your thyroid eye disease?

c15. Do you feel that you appear less often in photos than before you had thyroid eye disease?

c16. Do you try to mask changes in your appearance caused by thyroid eye disease?

Section D: How You Feel

Clinicians are well aware that emotions play an important part in most illnesses. Do not take too long over your replies; you immediate reaction to each item will probably be more accurate than a long thought-out response.

Read each item and underline the reply which comes closest to how you have been feeling in the last week.

D1. I feel tense or 'wound up':	Most of the time A lot of the time From time to time, occasionally Not at all
D2. I still enjoy the things I used to enjoy:	Definitely as much Not quite so much Only a little Hardly at all
D3. I get a sort of frightened feeling as if something awful is about to happen:	Very definitely and quite badly Yes, but not too badly A little, but it doesn't worry me Not at all
D4. I can laugh and see the funny side of things:	As much as I always could Not quite so much now Definitely not so much now Not at all
D5. Worrying thoughts go through my mind:	A great deal of the time A lot of the time From time to time but not too often Only occasionally
D6. I feel cheerful:	Not at all Not often Sometimes Most of the time

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D7. I can sit at ease and feel relaxed:	Definitely Usually Not often Not at all
D8. I feel as if I am slowed down:	Nearly all the time Very often Sometimes Not at all
D9. I get a sort of frightened feeling like 'butterflies' in the stomach:	Not at all Occasionally Quite often Very often
D10. I have lost interest in my appearance:	Definitely I don't take as much care as I should I may not take quite as much care I take as much care as ever
D11. I feel restless as if I have to be on the move:	Very much indeed Quite a lot Not very much Not at all
D12. I look forward with enjoyment to things:	As much as ever I did Rather less than I used to Definitely less than I used to Hardly at all
D13. I get sudden feelings of panic:	Very often indeed Quite often Not very often Not at all
D14. I can enjoy a good book, or radio, or TV programme:	Often Sometimes Not often Very seldom

Date _____ Code _____

E1. Does your thyroid eye disease impact your daily living in any way other than those described here?

E2. Did someone help you to fill out this questionnaire? **Yes** **No**

E3. If 'Yes', who assisted you? _____

E4. Do you have any comments about this questionnaire?

Many thanks for your invaluable participation

***Please now return your fully completed questionnaire
to the Researcher***

If you are concerned by any issues raised by this questionnaire and you would like to discuss them further, please do not hesitate to contact us at the Centre for Appearance Research and we will be happy to put you in touch with the appropriate services.

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