Skills for Growing Up – Epilepsy ‘On my way’

12 – 16 year

The Skills for Growing Up – Epilepsy is based on the Dutch Skills for Growing Up tool developed by the University Medical Center Groningen, Rehabilitation Center Blixembosch, Mytylschool Eindhoven, Erasmus Medical Center Rotterdam and TransitieNet on the basis of the original Skills for Growing Up (Holland Bloorview Kids Rehabilitation Hospital in Toronto, Canada). The icons used are developed by Op Eigen Benen in collaboration with TransitieNet

ROTTERDAM UNIVERSITY OF APPLIED SCIENCES
Research Centre Innovations in Care
Academisch Centrum voor Epileptologie Kempenhaeghe & Maastricht UMC+
Op Eigen Benen nu
FNO zorg voor kansen

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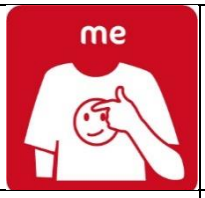
Me 		Date:	Date:	Ready V
1	I know I have a right to privacy (privacy means that you can do things without too much interference from others)	Yes / No	Yes / No	☐
2	I know I can participate in making important decisions concerning myself	Yes / No	Yes / No	☐
3	I know that, from the age of twelve, I have a shared responsibility with my parents or guardians concerning treatment or medical care	Yes / No	Yes / No	☐
4	I know what I must do or how I must act in order to get things arranged	Yes / No	Yes / No	☐
5	I can stand up for myself in the places where I go regularly (school, home, shops, library, sports club, online)	Yes / No	Yes / No	☐
6	I know who I can go to if life gets tough	Yes / No	Yes / No	☐
7	I'm satisfied about my appearance	Yes / No	Yes / No	☐
8	I know 3 physical changes that occur in boys and girls during puberty	Yes / No	Yes / No	☐
9	I can tell others what I have and what are the practical implications for me (friends, at school, family)	Yes / No	Yes / No	☐
10	There's always somebody nearby who knows about my epilepsy and its consequences	Yes / No	Yes / No	☐
11	I know where I can find reliable information about epilepsy, nutrition and sexuality	Yes / No	Yes / No	☐

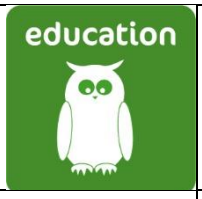
Healthcare		Date:	Date:	Ready V
1	I know what healthy and unhealthy eating and drinking is	Yes / No	Yes / No	☐
2	I follow a diet and understand why I do	Yes / No	Yes / No	☐
3	I know why smoking, alcohol and drugs are dangerous for my health	Yes / No	Yes / No	☐
4	I know who my medical care givers are and why I am there	Yes / No	Yes / No	☐
5	I make my own appointments with the doctor and other healthcare providers	Yes / No	Yes / No	☐
6	I understand what the doctor tells me	Yes / No	Yes / No	☐
7	I ask my own questions during a consultation with a doctor and/or other healthcare providers	Yes / No	Yes / No	☐

8	I answer questions that the doctor or other healthcare providers ask	Yes / No	Yes / No	☐
9	Once in a while I go alone to the appointments with the doctor and other healthcare providers	Yes / No	Yes / No	☐
10	I take part in decisions concerning my own treatment	Yes / No	Yes / No	☐
11	I have an overview of my own medical information	Yes / No	Yes / No	☐
12	I discuss the type of care I will need in the future with my doctor (transition clinic, adult care)	Yes / No	Yes / No	☐
13	I discuss the prospect for my epilepsy in the future	Yes / No	Yes / No	☐
14	I know why taking my medication is important	Yes / No	Yes / No	☐
15	I know the possible side effects of my medication	Yes / No	Yes / No	☐
16	I know the implications of fatigue for my epilepsy	Yes / No	Yes / No	☐
17	I know the implications of stress for my epilepsy	Yes / No	Yes / No	☐

Living and ADL		Date:	Date:	Ready V
1	I know what I must do in case of an emergency	Yes / No	Yes / No	☐
2	I manage my daily care alone (choosing my clothes, washing)	Yes / No	Yes / No	☐
3	I know that supervision is required when I when I take a bath/shower	Yes / No	Yes / No	☐
4	I am responsible for a number of household chores	Yes / No	Yes / No	☐
5	I know whether I can be home by myself	Yes / No	Yes / No	☐
6	I sometimes do the shopping	Yes / No	Yes / No	☐
7	I sometimes cook (with my parents/others)	Yes / No	Yes / No	☐
8	I have access to my own bank account	Yes / No	Yes / No	☐

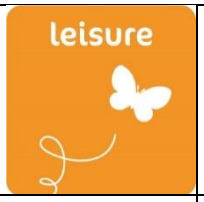
Relationships		Date:	Date:	Ready V
1	I spend time with my friends after school	Yes / No	Yes / No	☐
2	I can make contact with other kids	Yes / No	Yes / No	☐
3	I know how to safely use internet on a tablet or computer	Yes / No	Yes / No	☐

4	I can take into account what is important to my sisters, brothers and parents	Yes / No	Yes / No	☐
5	I can set boundaries in a care relationship in which supervision plays a role	Yes / No	Yes / No	☐
6	I can set boundaries in a romantic relationship	Yes / No	Yes / No	☐
7	I know what safe sex is and why it is important	Yes / No	Yes / No	☐
8	I know about different contraceptives and how to obtain them	Yes / No	Yes / No	☐
9	I dare to ask my doctor questions about puberty and sexuality	Yes / No	Yes / No	☐
10	I know that epilepsy medication can influence anti-contraceptives (such as the pill)	Yes / No	Yes / No	☐
11	I'm aware of the influence sexual arousal can have on my epilepsy	Yes / No	Yes / No	☐
12	I know about the influence my epilepsy has on my sexuality	Yes / No	Yes / No	☐

Education 		Date:	Date:	Ready V
1	I know what type of support and approach I need in order to do well in school	Yes / No	Yes / No	☐
2	I know the organizations and people that I can ask for help	Yes / No	Yes / No	☐
3	I know what my abilities and interests are when considering my career choice	Yes / No	Yes / No	☐
4	I discuss my plans after secondary school with others	Yes / No	Yes / No	☐
5	I do my homework independently	Yes / No	Yes / No	☐
6	I plan my own agenda	Yes / No	Yes / No	☐
7	I know my medication can cause concentration problems	Yes / No	Yes / No	☐

Transportation		Date:	Date:	Ready V
1	I know if I can travel on my own (bike, bus, train, subway, taxi)	Yes / No	Yes / No	☐
2	I head out onto the street on my own (bike, walking)	Yes / No	Yes / No	☐

Sports		Date:	Date:	Ready V
1	I exercise regularly (walking, biking, sports)	Yes / No	Yes / No	☐
2	I belong to a sports team or a gym	Yes / No	Yes / No	☐
3	I know certain sports can be dangerous because of my epilepsy (such as swimming without supervision)	Yes / No	Yes / No	☐

Leisure activities 		Date:	Date:	Ready V
1	I have a hobby	Yes / No	Yes / No	☐
2	I belong to a club or association (not sports related)	Yes / No	Yes / No	☐
3	I participate in extracurricular activities	Yes / No	Yes / No	☐
4	I go out with others (to the movies, to the city)	Yes / No	Yes / No	☐
5	I know what to arrange and take with me if I stay over at someone's house	Yes / No	Yes / No	☐
6	I sometimes go away for a few days without my parents	Yes / No	Yes / No	☐

Work		Date:	Date:	Ready V
1	I am looking into a part-time job, volunteer work or regular work	Yes / No	Yes / No	☐