

**“Every Child has the
Right to...”**

**2nd International Young Carers
Conference**

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Internet-delivered support for children and adolescents

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Background

- Children and youth of today are comfortable using Internet
 - Increasingly, information and self-management programs are internet-based
 - Available on a national level – and beyond?
-
- Multiple sclerosis - a challenge for the whole family



Background

Parents' chronic disease does affect children both in negative and positive ways

- Effects of the total strain
- Everyday tasks at the expense of their own needs
- Emotional distress implies extra burden
- More mature, independent and empathic than their peers

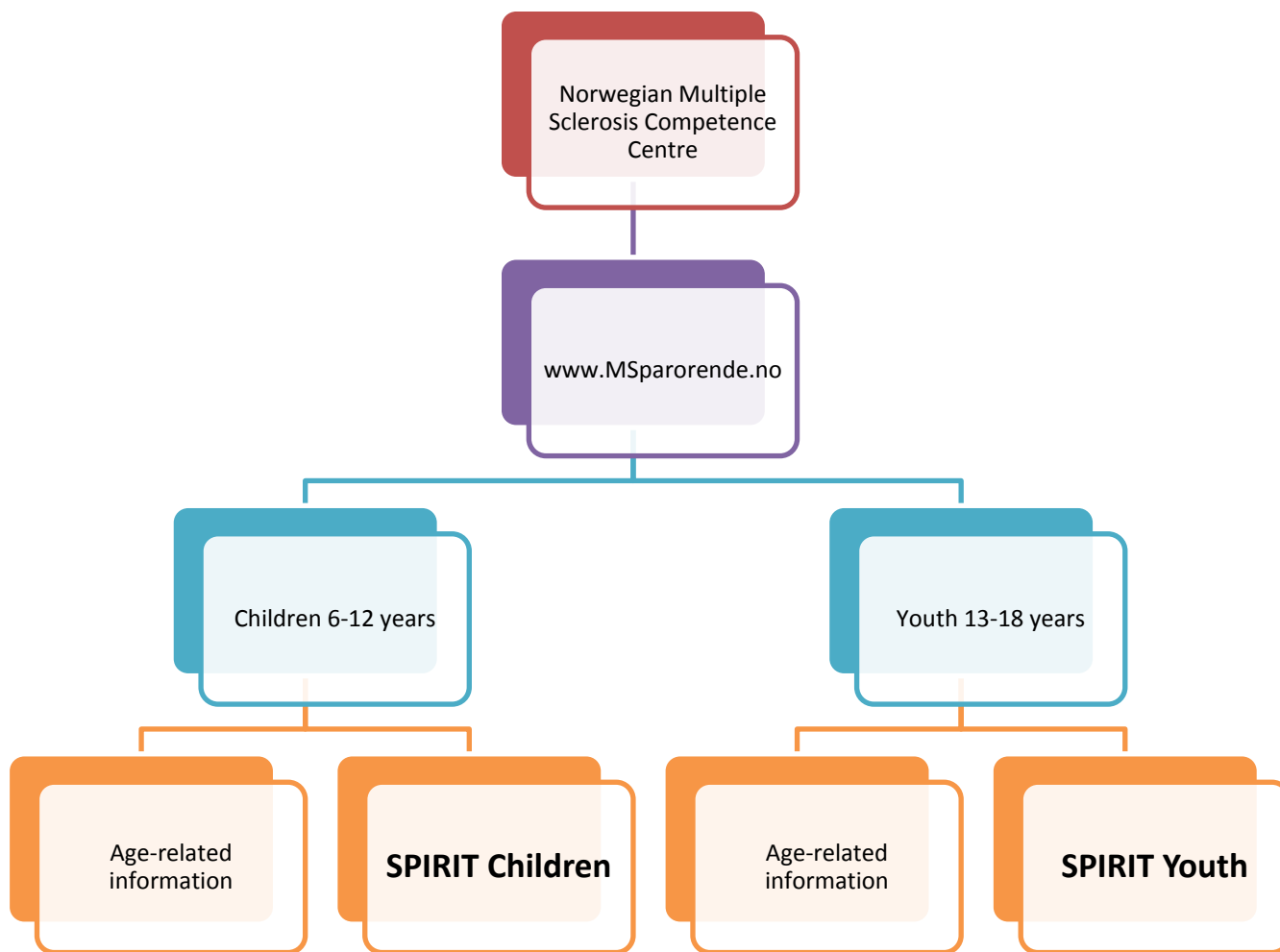
- Bogosian, A., Moss-Morris, R. & Hadwin, J. (2010) Psychosocial adjustment in children and adolescents with a parent with multiple sclerosis: a systematic review. *Clinical rehabilitation*, 24, 789-801
- Bogosian, A., Hadwin, J., Hankins, M. & Moss-Morris R. (2015) Parents' expressed emotion and mood, rather than their physical disability are associated with adolescent adjustment: A longitudinal study of families with a parent with multiple sclerosis. *Clinical Rehabilitation*, 1-9.
- Mauseth, T. & Hjälmhult, E. (2016) Adolescents' experiences and coping on parental multiple sclerosis: a grounded theory study. *Journal of Clinical Nursing*, 25: 856-865.

Methods – team and work process

- Multidisciplinary team:
 - Kjell-Morten Myhr, professor in neurology
 - Torild Mauseth, public health nurse/ project leader
 - Liv Solfrid Øvstebø Berge, specialist in psychology
 - Anne Britt Rundhovde Skaar, MS-nurse
 - Changetech, e-health company
 - Supported by Sanofi-Genzyme, medical company

- Development of website and self management programs





www.msparorende.no



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gjør deg
tryggere

Our aim for the children:

Be a good friend to yourself!

When children with parental illness receive information about the condition and support in handling everyday life, this may lead to less emotional distress and a higher quality of life.

- Pakenham KI & Bursnall S (2006) Relations between social support, appraisal and coping and both positive and negative outcomes for children of a parent with multiple sclerosis and comparisons with children of healthy parents. *Clinical Rehabilitation* 20; 709-723.
- Horner, RM (2012) Interventions for children coping with parental multiple sclerosis: A systematic review. *Journal of the American Association of Nurse Practitioners* 25: 309-313.
- Huang J.S., Terrones L., Tompane T., Dillon L., Pian M., Gottschalk M., Norman, G.J. & Bartholomew L.K. (2014) Preparing adolescents with a chronic disease for transition to adult care: a technology program. *Pediatrics* 133(6); 1639-1646.
- Stinson, J, Wilson R, Gill N, Yamada J & Holt J (2009) A systematic review of Internet-based self-management interventions for youth with health conditions. *Journal of Pediatric Psychology* 34(5); 495-510.

Common structure for SPIRIT Children and Youth

- **8 weeks**
- **1/ week**
- **15-20 min/ day**
- **PC, tablet or cellphone**
- **Registration via e-mail**
- **Free of charge**



 **SPIRIT BARN**

- **7 weeks**
- **1/ week**
- **15-20 min/ day**
- **PC, tablet or cellphone**
- **Registration via e-mail**
- **Free of charge**

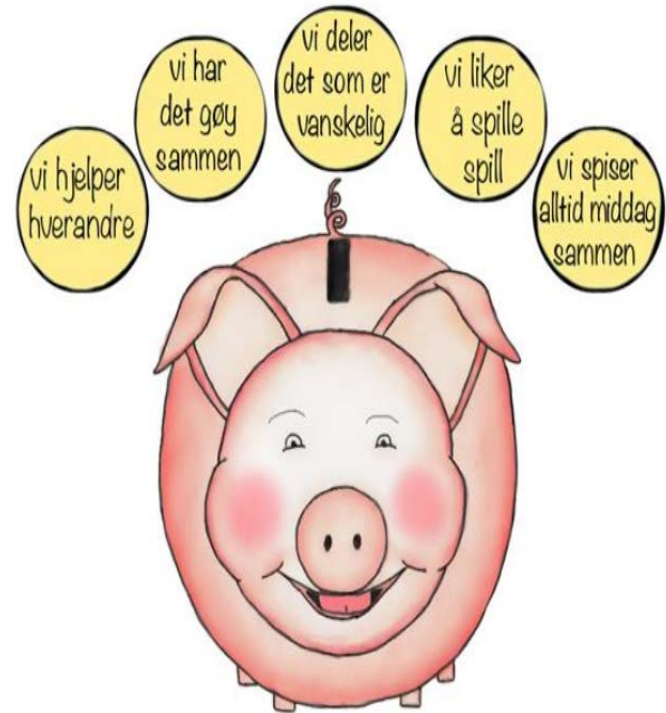
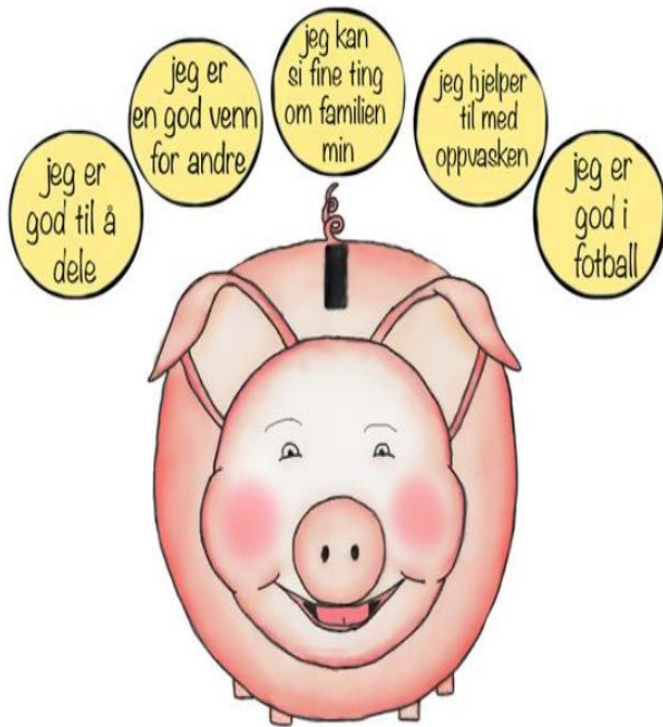


 **SPIRIT UNGDOM**



SPIRIT CHILDREN

Example: The family piggybank



Webster-Stratton, Carolyn. The Incredible Years: A trouble-shooting guide for parents of children aged 2-8 years. Seattle, WA: Incredible years, 2006.



SPIRIT YOUTH

The program speaks directly to the youth

The image displays three overlapping screenshots of the SPIRIT UNGDOM program interface. The central screenshot, titled "SPIRIT UNGDOM DAG 1", features a video player with the title "Gutt 15 år, forteller om da pappa fikk MS." and a progress bar. Below the video, there is a button labeled "Eksempler på andre tanker du kan ha" with a right-pointing arrow. To the left of the video player is a large image of a young man with dark hair, looking thoughtfully to the side with his hands clasped under his chin. To the right of the image is a text box titled "Du tenker på sykdommen." containing the following text: "Når du opplever at mor eller far blir alvorlig syk, er det helt naturlig at du tenker på sykdommen og hva den kan medføre for deg og familien din framover. Du kan ha mange spørsmål om hva MS er, hva sykdommen kommer av, hvordan den kan behandles og hvordan det kommer til å gå med den syke. Vanlige spørsmål er for eksempel: 'Hvordan påvirker MS kroppen og hjernen?' 'Kan man dø av MS? Er sykdommen arvelig?'. Du kan finne mye informasjon om dette på www.MSpårørende.no/www.MSparørende.no". At the bottom of this text box is a button labeled "På neste side kan du lytte til en lydfil..." with a right-pointing arrow. The top-left screenshot, titled "SPIRIT UNGDOM DAG 2", shows a section titled "Tenk tilbake i tid..." with the instruction "Tenk tilbake på en situasjon eller opplevelse som har vært litt vanskelig for deg." Below this are several text input fields for reflection: "Hva var situasjonen?", "Hvilke tanker hadde du?", "Hva følte du?", "Hvilke tanker kunne vært hjelpsomme?", and "Hvilke følelser tror du disse tankene hadde gitt deg?". At the bottom of this screenshot is a button labeled "Fortsett å gjøre øvelsen denne uken" with a right-pointing arrow.

- Berge, T. & Repål, A. (2015) Håndbok i kognitiv terapi. Oslo, Gyldendal Akademisk.



When you have a sick parent, you very easlily take on too much responsibility at the cost of your own needs.

When you learn to think positively about yourself, and that your own needs are important, it becomes easier to choose how you would like to spend your time. This becomes possible to do without feeling bad or sad.

UKE 3: ABC-MODELLEN

SITUASJON	TANKER	FØLELSER	HJELPSOMME TANKER.....	HANDLING
Eks. Pappa spør om jeg kan klippe plenen i ettermiddag, men jeg har egentlig en avtale med Pål og Henrik om å møtes i byen.	Jeg bør klippe plenen i dag, ellers blir pappa stresset over at det ikke blir gjort. Nå må jeg avlyse det med Pål og Henrik igjen.	Irritert Oppgitt Dårlig samvittighet ovenfor vennene	Jeg kan fortelle pappa at jeg har en avtale, og at jeg klipper gresset i morgen ettermiddag. Om det regner, gjør jeg det neste dag med fint vær.	Jeg bestemmer meg for å si til pappa at jeg har en avtale med Henrik og Pål, og at jeg klipper gresset en annen dag.



Experiences so far.....

SPIRIT Children: 653 visitors/ 75 registered
November 2015 – May 2017

SPIRIT Youth: 327 visitors/ 47 registered
December 2016 – May 2017



- Norwegian Directorate of Health (2010) *Barn som Pårørende (Children as Next of kin)*: Rundskriv til lov av 2.Juli1999 nr. 61 og lov av 2. Juli 1999 nr. 64. Norwegian Directorate of Health, Oslo.
- Stinson J., Wilson R., Navreet G., Yamada J., Holt J. (2009) A Systematic Review of Internet-based Self-Management Interventions for Youth with Health Conditions. *Journal of Pediatric Psychology*, 34 (5): 495-510.

Some quotations:

Spirit Children:

- «Thank you for the nice program. We have talked about some new things in our family, and we have learned new things. This was good for both children and adults.»

Spirit Youth:

- «The tips have been helpful. I'll be using them.»
- «The whole program has been helpful, it has helped me understand that not everything has to be about putting others' needs first, but that I and my feelings are also important. It has been fun to recognize my situation in the stories that have been told.»