

# Planning, Implementing & Evaluating Programs for Kids Who Have a Parent With MS

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*Seeking the Cure.  
Providing the Care.*



# How and why does parental Multiple Sclerosis (MS) affect kids?

- Age at diagnosis
- Typical symptoms
  - ◆ Visible (generally physical)
  - ◆ Less visible (continence, vision)
  - ◆ Invisible (cognitive, sensory, fatigue)
- Unpredictability
- Financial impact
- Impact on family

# Project Plan

- Determine need and goal for the project.
  - ◆ Need: there are numerous stressors on children who have a parent with MS,
  - ◆ Goal: to provide specific supports for school-age children of parents with MS.

## Objectives

- Develop & access materials & other resources

## Strategies

- To develop & access audio/visual & written materials for children, parents & relevant professionals



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# Project Plan (cont)

## Objectives

- Interaction with target group through individual & group activities

## Strategies

- Design & operate chat room & email contacts on a statewide & potentially National basis.
- Plan & operate school holiday camps & one day programs for specific age groups.
- Plan & operate parent support groups as appropriate.



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# Project Plan (cont)



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## Objectives

- Collaboration & partnership with key organisations & other interested parties to extend the reach & impact of the program.

## Strategies

- Form strategic relationships with Carers Queensland, UQ, DSQ, DFACS.
- Involve UQ and Carers Qld in planning & implementation of project activities

# Project Plan (cont)



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## Objectives

- Advocate on behalf of children of people with MS with service providers and funding bodies

## Strategies

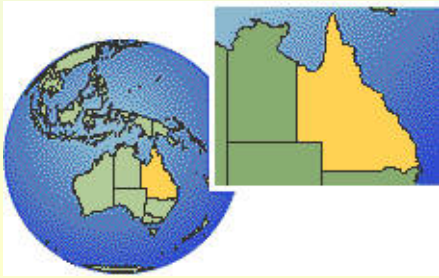
- Sound documentation & internal evaluation of all project performance
- Proactive, targeted initiatives to influence key organisations, reviewed annually

## Issues we considered when planning the kids program

- Need to publicise the new, additional focus of client services
- What resources did we already have?
  - ◆ Video
  - ◆ Brochure for teachers
  - ◆ Search for kids flier
- Equitable service vs. convenience sample vs. time constraints

# No Organisation is an Island!

- Advantages of networking
- Forums & focus groups – why they are a good investment in time
- Examples of organisations willing to network & share information and resources
- Working with University students – a win-win situation.



# Finally! Face-to-face “Fun in the Sun Festivities”



- Search for an existing program
- Eureka! Let's modify the siblings program.

Kate Strohm

Director, Siblings Australia

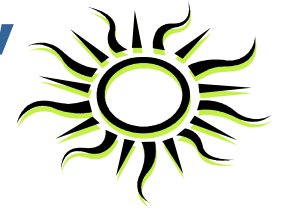
Women's & Children's Hospital

South Australia

Ph (08) 8161 6737

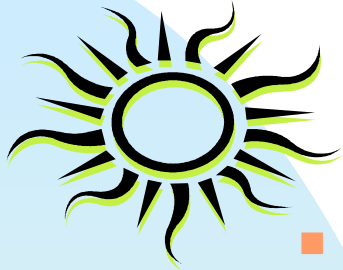
[www.siblingsaustralia.org.au](http://www.siblingsaustralia.org.au)

# Aims of “Fun in the Sun”



- To equip the children with coping skills that enable them to deal effectively with the added burdens that are placed on them as part-time carers for their parent with MS.
- To reduce the sense of isolation in the children by linking with other children and teenagers who also have a parent with Multiple Sclerosis, and encouraging ongoing contact through email, post, phone conversation etc.
- To access information about MS and living with MS in a face-to-face, interactive, non-threatening, supportive and age appropriate manner.
- To enable the children to participate in fun, enjoyable activities that their school friends regard as a matter of course

# Future Aims of “Fun in the Sun”



- To find local support people to continue supporting the children after the camp program has finished
- To educate local health and service providers about the needs of this group of children, and to equip them with the resources to continue providing appropriate information and support.



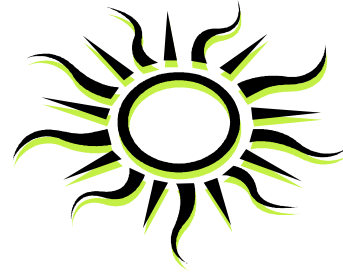
# Camp Program

	Sun 14th	Mon 15th	Tues 16th	Wed 17th	Thur 18th	Fri 19th	Sat 20th
A M	<p>9.30am Arrival &amp; morning tea</p> <p>Group session: Getting to know each other</p>	<p>Group Session: Friendly and not- so-friendly feelings</p>	<p>Group Session Communica tion Skills and Thought power</p>	<p>Group Session: Problem squashing</p>	<p>Theme Park</p>	<p>Group Session: Wiping out worries</p>	<p>Pack and tidy up</p> <p>Pick up time: 9:30am</p>
P M	<p>Group Session: Differences and disabilities</p>	<p>Boating and Motor bike riding</p>	<p>Mini-Golf</p> <p>Craft Activities</p>	<p>Boating</p> <p>Cooking</p>	<p>Theme Park</p>	<p>Group Session: Leaving stronger and supported</p> <p>Craft Activities</p>	

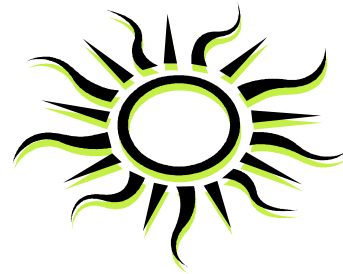
# Fun in the Sun with the Ulysses bike club



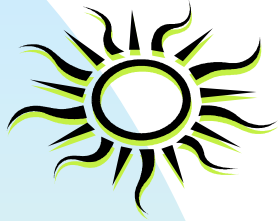
# Fun in the Sun – boating with Michael



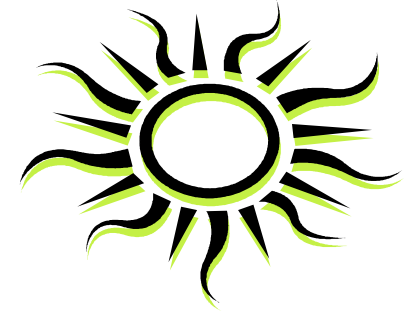
# Fun in the Sun – mini golf



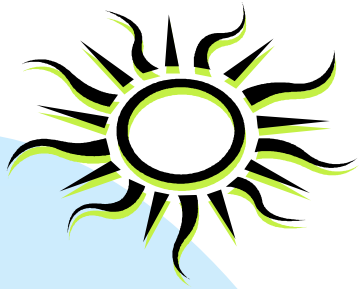
# Fun in the Sun at Dreamworld



# Focus of the Group sessions



- Getting to know you
- Differences & disabilities
- Friendly & not-so-friendly feelings
- Communication skills
- Thought power
- Problem squashing – DECODE
- Wiping out worries
- Leaving stronger & supported



# Getting to Know You

## Group Aims:

- Allow all the group participants to get-to-know each other
- Explore the participants' expectations of the group
- Explore the purpose of the group



# Review of application form required

## Social skills information

- Does your child relate well & happily with siblings, friends & other children at school?
- Does your child need lots of encouragement to join in social & group activities with people his/her own age?
- The group sessions encourage children to think about their feelings. Please indicate if there have been or still are any issues in your child's life which may make this difficult for him/her?

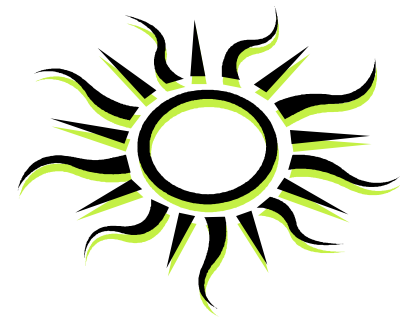


# Session One: Differences & Disabilities

## Group Aims:

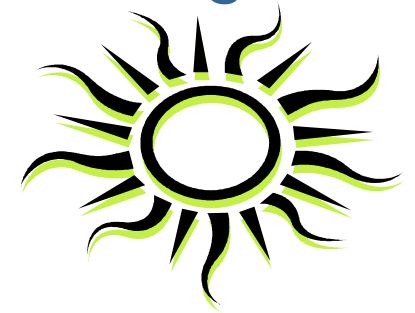
- To explore the differences and similarities that participants have with their families and with others, recognising their uniqueness
- To build knowledge and understanding about disabilities
- To identify activities participants enjoy doing with and without their parent with MS.

“I really learnt a lot today about MS”  
14 year old boy – mother with MS



## Session 2: Friendly and Not-so-friendly Feelings

### Group Aims:



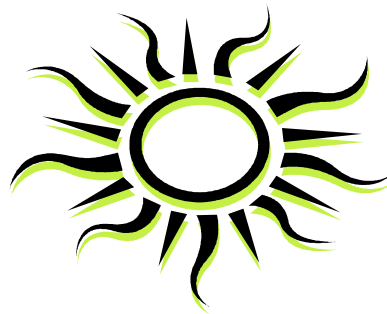
- To learn to identify a range of feelings
- To enhance awareness of feelings regarding having a parent with MS
- Understanding that it is OK to have negative feelings as well as positive feelings
- To explore the expression of feelings in an appropriate way, particularly the more negative ones
- To identify and build support networks and recognise types of support available

# Session 3: Communication Skills

## Group Aims:

- To learn about the importance of communication and about basic communication techniques.
- To applying knowledge about MS to ideas about communicating with the parent with MS.

12 year old boy “It was the best session yet”.



14 year old boy “It helped me understand how to communicate.”

# Session 4: Thought Power

## Group Aims:

- To learn about how the types of thoughts people have about situations impacts upon how they feel
- To teach children how to identify unhelpful thoughts
- To teach children how to replace unhelpful thoughts with more helpful thoughts



# Session 5: Problem squashing & DECODING

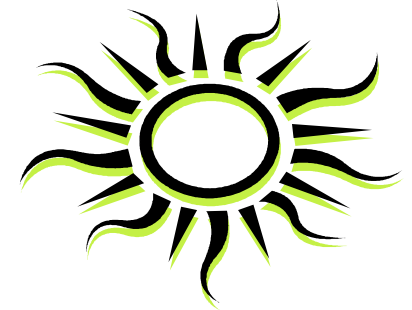
## Group Aims:

- To learn and demonstrate problem-solving skills in order to cope with the various challenges faced by kids with a parent with MS
- To recognise that they are not alone in their experiences
- To learn specific strategies about how to deal with various challenges, such as how to tell others about their parent's MS, how to deal with teasing, how to manage missing out on things their friends do.



# The DECODE Problem–Solving Formula

- **D** = Detect the problem, define it & decide what you want to happen
- **E** = Explore different solutions to the problem
- **C** = Consider the consequences & choose a solution
- **O** = Organise a plan
- **D** = Do it! Carry out the solution
- **E** = Evaluate. Think about how it went



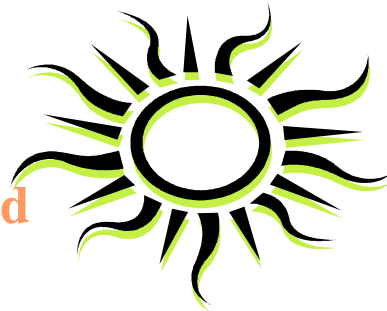
“Today helped me to let my friends know about mum’s MS. Thankyou” 14 year old

# Session 6: Wiping out worries

## Group Aims:

- To learn, identify and apply coping skills to deal with the more challenging times
- To understand that some problems are able to be solved and some are not
- Learn strategies to cope emotionally if the problem cannot be solved, such as relaxation training or journal writing.

“It was really awesome. I was so relaxed & ready for anything. I was not angry at all”. 12 year old



“The happy place was the best. I’ll use it to visit when I’m angry or need time alone”. 14 yo

# Session 7: Leaving stronger & supported

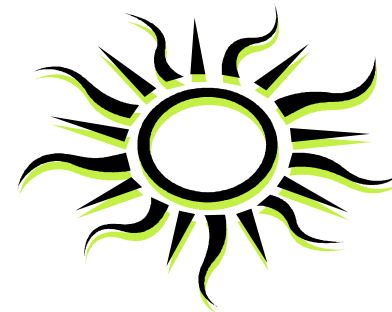
## Group Aims:

- Review and reflect on past learning and the group experience
- Enhance knowledge about personal strengths and the strengths of their family member with MS
- Establish longer-term supports with each other



“I didn’t know that MS could make my mum grumpy. Next time she’s grumpy I’ll blame the MS, not her”. 12 year old girl.

# Making treasure & memory boxes



# Friends for Life



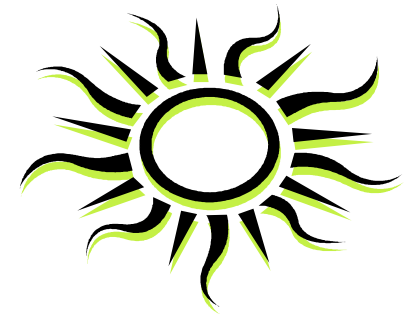
“It was cool being with other kids that know about MS. I didn’t have to pretend that my family was the same as everyone else”.

“Before the camp, my daughter didn’t tell any of her school friends what the camp was for. Now she’s wanting her teacher to ask her about it. She says ‘MS is nothing to be ashamed of!’” Mother of 12 year old daughter.



# Fun in the Sun Participant Book

- Worksheets for all sessions combined into one book
- Summaries of important messages
- Contact details of MS Society, camp leaders and other kids at the camp
- Relaxation scripts
- Tool for family discussions



# Feedback form for each group session



## 5 point Likert scale on each of 4 statements for each group session

- People did not always listen to me vs. People listened to me
- What we did and talked about was not really that important to me vs. What we did and talked about were important to me.
- I did not like what we did today vs. I liked what we did today.
- I wish we could do something different vs. I hope we do the same kind of things next time.

# Research Component - children

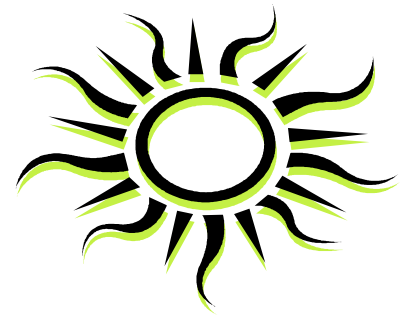
**Before the camp, on final day of camp and one month after camp.**

- Demographics
- Support, feelings & attitude toward life, how you cope with stress
- Your family & feelings about your family
- Your experience of helping your parent who has MS
- What you know about MS

# Parental Involvement in the program

- Each family was given a parent handbook about the aims of the group sessions at the start of the camp.
- Parent with MS completes a research questionnaire before the camp and one month after the camp.

“It was great meeting some of the other parents when we dropped the kids off on the first morning.” Mother of camper.



# Research component – parent with MS

## Before the camp and one month after the camp

- General information about you & your MS
- Feelings and attitudes toward life
- Your family & usual communication styles
- Your perceptions of your child's coping skills

“The kids are hatching plans to spend time in the school holidays together. We live a long way apart, so they can't catch up during term time, but maybe they can stay with each other in the holidays. They are already chatting to each other on the net!” Mother with MS.

# One month follow up – qualitative data

## Mother 1

They provided him with very good info in regards of how to cope when I get upset with this illness. He is quick to get involved when I am down.

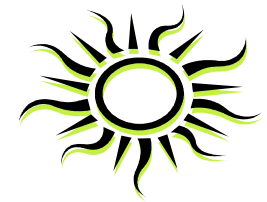
I think it has helped the family as a whole. He has helped out more around the home. He does more for both of us and not one grumble. He is truly a great kid anyway but we have learnt to appreciate him more. We cope better as a family.

## Son 1

I have learned more about MS and everyone gets worse at different rates.

She didn't have to worry about me for a week.

They had time to themselves



# One month follow up – qualitative data

## **Mother 2**

Overall he has met up with other children in the same boat and this has been a great help to him.

He has a little more understanding that I am not the only one who has limitations, heaps of others do too.

He has started to form relationships with some of the people who are already supportive to me (sic MS Society staff). We are not alone!

## **Son 2**

The camp taught me about MS.

I met other kids with parents with MS.

I got to know staff and carers who help mum.

Mum is happy there is a support network for me.



# One month follow up – qualitative data

## **Mother 3**

The camp helped my girls learn more about MS. They made some wonderful new friends ....as they understand what each other is going through.

It has helped them to feel more comfortable about talking to others about their mum having MS.

It has helped facilitate further communication between us about my MS.

## **Daughter 3a**

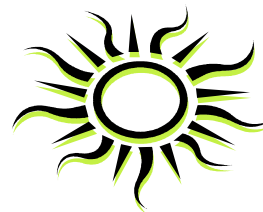
I made friends that know what I am going through.

## **Daughter 3b**

I have met kids whose parent is worse than mine.

I learned things about MS and that I can help her more.

We can all help mum and have learnt how to solve problems.



# One month follow up – qualitative data

## Mother 4

The camp made them more aware of my illness and how I feel sometimes. I thought I had a bladder infection last week and they both chirped up it was probably the MS. And it was! They certainly remember more than I do.

They learnt a little more consideration for each other and my son doesn't whine so much about washing up as he learnt other kids do that too.

It made them a bit more tolerant of everything

## Son 4

The camp helped a lot. I met other people in the same sort of situation and learnt to deal with problems.



# One month follow up – qualitative data

## Mother 5

The camp gave us all the chance to unite and discuss MS as a family.

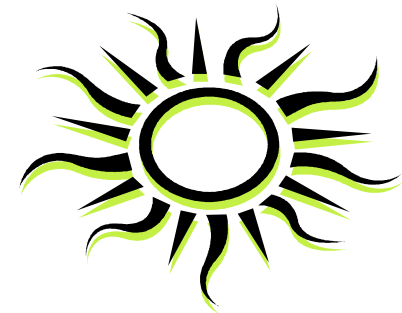
I feel sometimes on good days they forget that fatigue takes over, and although we wish to be treated normal we need understanding and rest. This is often not forthcoming which leads to frustration and despair.

The camp allowed all of us to accept MS as being “real”.

## Daughter 5

It has helped me to understand more about MS.

I think my mum had a good rest while I was at the Fun in the Sun Camp.



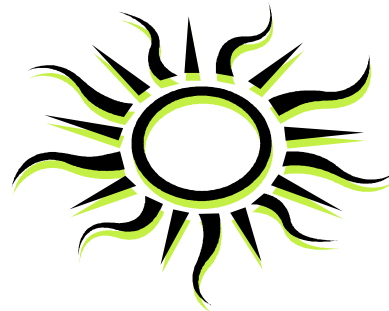
# One month follow up – qualitative data

## Mother 6

The camp helped the children by showing them the differences in MS symptoms.

It explained about MS as I did, but as someone else said it they listened. Now they know how MS affects me.

The camp gave everyone a clearer understanding of the way MS affects each family member.



## Son 6

Since the camp I've taken a little more care towards her, as I know what the symptoms are and when they occur, so I know when to help.

It has brought us closer together, to help us have a bigger understanding of each other

# Fun in the Sun Inaugural Campers Oct 04



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