



Smith-Magenis Syndrome (SMS) Camp Training



We acknowledge the Traditional Owners of the land

Breakaway is located on Darkinjung country, which extends from the Hawkesbury River in the south, to Lake Macquarie in the north, from The McDonald River and Wollombi up to Mt Yengo in the west, to the Pacific Ocean in the east, and we wish to acknowledge them as Traditional Owners.

We would also like to pay our respects to their Elders, past and present, and to Aboriginal Elders of all nations.

By completing this training session you will

- Be introduced to the U.S. Team and the local Breakaway leadership team.
- Understand the SMS Camp objectives.
- Learn the basic characteristics and signs and symptoms of SMS.
- Be equipped with strategies to successfully manage a range of presenting behavioural problems that may occur on the camp.

**This online training should take approximately
30 minutes to complete**

Our Mission Statement

Camp Breakaway is a non-profit, charitable organization committed to enhancing the lives of all people with a disability, at the same time allowing respite for families and carers

Please take the time to read this important document

(Click on each link for access)

Link to NDIS Code of Conduct

<https://www.nwss.org.au/support/wp-content/uploads/NDIS-Code-of-Conduct.pdf>

SMS Camp Objectives

- To celebrate the achievements of all SMS children.
- To give the SMS child a chance to mix with other SMS children in a similar situation.
- To provide an environment where these families can enjoy a holiday together.
- To give the siblings of SMS children an opportunity to talk with other siblings in a similar situation.

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SMS CAMP OBJECTIVES (2)

- To create an atmosphere where parents feel comfortable to discuss their situation with parents in a similar position. This then often leads to the establishment of a support network, that continues long after these camps end.
- To pamper the parents and allow 'parents only' time, whilst providing entertainment for the SMS child and their siblings.
- To provide information to new parents.
- To raise public awareness of SMS.

Breakaway SMS Camp Coordinators

SMS Camp Coordinator <NAME>

SMS Parent Hosts <NAME>

SMS Kids Coordinator <NAME>

Siblings Program Coordinator <NAME>

Lodge Coordinator <NAME>

Nursing Coordinator <NAME>

Photography <NAME>

WELCOME Team USA



← Professor Ann Smith

Gail Kopp →



Introducing

Ann C.M. Smith, M.A., D.Sc. (Hons)

Ann is a board certified genetic counsellor who has worked in medical genetics field for over 30 years.

Ann co-discovered SMS.

At The National Institutes of Health Ann heads the multi-disciplinary SMS Research Team and is the adjunct principal investigator of two SMS research studies.



Introducing



Gail Kopp lives in Wisconsin (near Chicago) with her husband Al and two daughters, Alanna and Elizabeth, who has SMS.

Gail is currently employed as a Forensic Nurse Examiner and Program Coordinator.

This is her 4th trip to Breakaway to help Ann with the SMS Research Clinic

What is Smith-Magenis Syndrome?

A complex developmental disorder that affects many parts of the body

The major features of this condition may include:

- **mild to moderate intellectual disability**
- **Delayed speech and language skills**
 - **Distinctive facial features**
 - **Sleep disturbances**
 - **Behavioural problems**

Signs and Symptoms

Physical Characteristics

Children with SMS can have:

- Facial features that include a broad, square face with deep-set eyes, full cheeks and a prominent lower jaw, a flattened Bridge of the nose, a downturned mouth and eyes looking in different directions
 - Low muscle tone
 - Curved spine (scoliosis)
 - Myopia (short-sightedness)
 - Short stature
 - Hoarse voice
 - Flat feet

Signs and Symptoms (2)

Cognitive Signs

Children with SMS can have:

- Developmental delay
- Mild to moderate intellectual disability
 - Speech delay

Signs and Symptoms (3)

Behavioural Signs

Children with SMS can have:

- Sleep problems
(e.g. may sleep during the day and be awake at night)
- Temper tantrums and aggressive problems
- Anxiety
- Attention difficulties

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Signs and Symptoms (4)

Behavioural Signs

Children with SMS can have:

- A tendency to injure themselves deliberately
- A tendency to hug themselves repeatedly
- Reduced sensitivity to pain and temperature
 - Eating difficulties
(with a preference for soft food)

Signs and Symptoms (5)

Medical concerns linked with SMS

Children with SMS can have conditions like:

- Ear abnormalities
(sometimes hearing loss)
- Heart and kidney defects
- Retinal detachment

Behaviour Management

Behavioural problems can appear with school or group socialisation.

Often comes in the form of self-aggressive acts like biting, head banging and picking at wounds (which can then become chronic).

First Introductions

- Let the child approach you first - taking a step back or getting to their level, this gives them a non-threatening approach.
- They can have a fight or flight response in anticipation of the meeting.
- Do not get into their space - although they may get into yours.



Good Behaviour / Bad Behaviour

- **No matter what type of behaviour you observe it is important to recognize that behaviour is a means of communication and it serves a function.**
- **It may be used to gain something, or escape something, but that behaviour serves its purpose to that person.**



Tips to enjoy your time volunteering as a carer

- **Decide now that you are going to have a great time.**
- **Familiarize yourself with the child you are assigned:**
 - **Likes,**
 - **Dislikes / triggers,**
 - **Enjoyed activities,**
 - **Nap times or rest times.**



Stay One Step ahead

- Practice speaking in a calm manner-even during a tantrum (let them borrow your calm).
- Ignore behaviours that are demanding attention.
- Plan ahead of time what and if you want to give out personal information.
- They have a great memory (watch out for your 'phone number).

Continued ➔

Stay One Step ahead (2)

- Will remember family members, your birthday and where you live.
- Get interested in medical procedures i.e....gory things.
- Offer choices that have the same outcome:
 - Example: “ Would you like to join us in the circle or do you need help?”, “ We are going to wash our hands would you like the bar of soap or the liquid?”

Distraction/Redirection/Avoid the triggers

- Look at that bird (pointing outside)...did I see a worm in it's mouth?
- Offer soft squishy toys to fiddle.
- Move to another activity.
- Praise desired behaviour.
- Ask for help, they love to be the helper.
- Send a message to another carer:
 - pre-planned written envelopes
 - Post it notes
 - Deliver heavy objects



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- **Do not get offended if your child does not take to you-it is not your fault and you may need to swap.**
- **In adolescence, an over interest can happen with the opposite gender:**
 - **Be aware of inappropriate touching.**
 - **You can use the phrase “that makes me uncomfortable/that’s inappropriate” or “can you help me have my own space?” or “I don’t like that.”**

Tantrums

- **Ignore**
- **Redirect**
- **Use visual cues**
- **Have a preferred adult make the request**
- **Choose your battle - it may be best for all just to move on.**
- **Remove others from the environment / remove the audience**
- **Safety of others trumps personal objects**

Super Siblings

- **May be protective of SMS sibling**
- **Want to hang around to see that their siblings needs are taken care of properly**
- **May use SMS attention to bond with other siblings**
- **May become embarrassed by sibling**
- **Praise the siblings they really are super**



Crisis Intervention

by Pauline Maniskas
(SMS Children's Team Leader)

Volunteer Medication

- All medication usage/dosage should be documented accurately on relevant camp form documentation in order to assist volunteer if requiring medication
- Medications brought to camp by volunteers must be kept safe & secure **away from guests**
- No sharing of medications - especially with/for guests
- Sleeping medication – **NOT** if responsible for guests overnight

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Volunteers can store their medication

- In your own locker.
- With the RN.
- In the valuables safe (Camp office).
- On your own person (use of a bum bag is recommended).
- Mixture of the above options.



**Thank you for
completing this
training session.**

Any Questions?
(See following page)



For more information

Please visit our website @

www.breakaway.org.au

or visit Facebook @

<https://www.facebook.com/campbreakaway>

or contact Breakaway on

(02) 4390 7624

Please continue to next slide 

Please exit 'Slide Show' mode now

Enter your details on the following slide to certify that you have completed this training module.

Then print out the completed slide, sign it, and deliver or send it to Breakaway.

We will use this information to update your volunteer record in our database to show that you have completed this training module.

This completed form is the only evidence that the module has been completed that Breakaway is able to accept.

Certification of completion of Module #7: Smith-Magenis Syndrome training session

**I have read and understand the Camp Breakaway Module 7
& agree to abide by the principles as outlined in this module.**

Name: _____

Date Completed: _____

Signature: _____

Please print out this completed form, sign it, and either deliver or send it to Breakaway.

We will use this information to update your volunteer record in our database to show that you have completed this training module.