

# **A HOLISTIC APPROACH TO PAEDIATRIC PALLATIVE CARE VERY SPECIAL KIDS - SIBLING SUPPORT**

**LYNNE TWAITS/FIONA McCALLINDEN**

**Family Support Worker, Very Special Kids  
Secondary Teacher, General Nurse, Accredited Emotional Release Counsellor  
for Children and Adolescents**

Very Special Kids is an organisation that improves the quality of life for families who have a child with a life threatening illness. We also continue to support families after the death of a child. Currently we support 440 families throughout Victoria – 140 of these families are bereaved. The majority of our work is made possible by commitment of 150 trained volunteers.

We offer the following services:

- Residential respite care centre and hospice
- In home volunteer support
- Hospital visitation program
- Support and counselling
- Sibling Support programs
- A range of bereavement services
- A broad range of holiday and weekend camps
- Social functions and outings for families
- Referrals and advice on social welfare and community resource services
- Provision of opportunities to enable sharing with families in similar circumstances
- Newsletters to families
- Reference library and video camera loan

Very Special Kids - Sibling programs evolved from a major evaluation of all Very Special Kids services carried out in 1996. Parents identified a need for 'Sibling Counselling' at that time. Due to practical and resource issues, it was decided to offer sibling group work to address this need. The sibling programs were developed into two streams, one for bereaved and the other for non-bereaved siblings.

Sessions are designed to be complete in themselves and form part of the ongoing sibling programs.

In addition Family Support Workers are vigilant to the need for 1:1 work with siblings at Very Special Kids.

**Programs:** use a variety of communication tools which includes sand tray and symbol work, art therapy and creative use of games and stories.

**Themes:** Each sibling program has a theme eg. space station, animals, circus. These themes allow for creativity in therapeutic and fun activities, room decorations and play.

**Attendance:** There is now a core group of children who attend most programs but new children join each time. The children range in age from 6 -15 years old.

### **PLANNING PRINCIPLES**

Our own experience of working in this field as well as literature and research informs us of some basic operating principles –

‘An emotional disturbance can be dealt with by giving it visible shape’ (CJ Jung)

- The experiential focus allows the children to explore the feelings and thoughts that operate in their lives, both conscious and unconscious.
- The emotional health of all family members is as important as physical wellbeing.
- Traumas too emotionally painful can be repressed from consciousness and become stuck (resulting in muscular tension). What is repressed has to come out and either explode into anger and aggression or implode into sickness and depression.
- Rage, anger and hate are normal reactions to being hurt; they cover deep grief.
- Outward expressions of anger, frustration and pain are encouraged in emotional release (yes & no, tug-of-war, the pillow jump).
- To be healthy, emotions need to move in a search and recognition for inner qualities of strength, hope and freedom (spirituality).
- Work towards alleviating feelings of isolation, normalise the experience of being a sibling in these circumstances.
- To provide a safe environment to express emotions, feel special and have fun, provide group identity and peer support.

In planning the Programs a number of considerations are taken into account. Some of the main areas that we have attempted to address are the following:

### **IMPACT ON SIBLINGS**

- Family patterns revolve around the ill child
- Sick child may absorb more attention, resources and finance.
- Anxiety and guilt that they are somehow responsible for sickness – older siblings may worry if their children will be affected by sickness.
- Siblings may have to act as a surrogate parent to a sick child or younger siblings; may affect their social life and cause them to question their long-term responsibility for the sick child.

- Siblings may feel pressure to succeed or excel when their sibling cannot.
- Siblings may experience confusion regarding parents changing reactions – grief cycles. This can impact on the overall family functioning.

**WHAT SIBLINGS WANT TO KNOW**

- The nature and extent of illness
- Cause of illness and how did it happen?
- Why did it happen?
- Did I contribute to its happening?
- Will it happen to me?

**The following are samples of non-bereaved sibling sessions.**

***VERY SPECIAL KIDS SIBLING CLUB (Animal Theme)***

- 9.30 Making badges, ID cards and welcome
- 9.30 Bingo
- 9.45 Introduce yourself and sick brother/sister
- 9.55 Rules
- 10.00 Choose an animal (symbols), share with the group (3 groups), debrief in big group
- 10.10 Animal mime. Animal walk and talk (large group)
- 10.20 Draw an animal that is most like you now
- 10.50 Put up on wall. Debrief in large group

**MORNING TEA AND PLAY TIME**

- 11.30 Limbo dancing
- 11.40 Draw a picture of your family as animals Small groups with discussion
- 12.05 Put on wall. Debrief as a large group
- 12.15 Pillows
- 12.25 Evaluation (video)
- 12.30 Certificates and gifts ID swapping  
Optional activities: hot spots, helicopters

**VERY SPECIAL KIDS SIBLING CLUB**

**TWO DAY PROGRAM (SPACE THEME)**

9:30am ARRIVAL

Music

FST Workers to meet with parents, others to commence name tag construction

9:45 Introduce today, eg: fun  
Hands up means stop talking

9:50 GETTING TO KNOW YOU ACTIVITY  
Space sheet, 3 questions to share in pairs and swap. Introduce each other. Questions:  
what is your favourite animal and why, what is your favourite TV show and why,  
who is your hero or favourite person and why?

10:00 THE CAPTAINS PLEDGE  
Light saver/talking stick, establish group rules and then hand out sheet to sign. Ask  
for a volunteer to read it out

10:10 LOOSEN UP ACTIVITIES/Emotional release for body and voice  
Moonwalk and talk, Jupiter jumping, sun skipping, throw meteor  
Yes/no, get off my back  
Mention we'll discuss how they can use these at home later

10:25 Make your own spaceship  
Introduce as their unique spaceship they can fly around in and visit lots of places and  
different time dimensions. Children to form into small groups and hang ships in the  
twilight zone. View the room with the fluorescent light

PHOTOS

BREAK: 11:00 (Rations) 20 Minutes

11:20 Re-group. Asteroid throwing  
Throw the asteroid and yell out the name of the person they are throwing to

11:25 THERAPEUTIC ACTIVITY (1) - Time travel, life journey  
Introduce concept of drawing three special/memorable times over your life, describe  
it as you imagine you are in your spaceship and you can travel back to the past and  
into your present. Drawing in small groups. Sharing in small groups of their journey  
after 20 minutes or throughout the drawing if appropriate

Prompt cards for facilitators in sharing will include: why is this important/unforgettable, who's there, what are you and the others doing, what's happening, I notice that ... tell me about..., who's there for you?, what helps when you feel that way, what did you feel at that time, how do you feel about it now? Did anyone notice similarities in their stories?... Praise strengths

Other activities for those who complete early: Assist child to get decorations to stick on their folder or to finish space ship or name tag or to colour in a space picture. Ensure child stays in their group

11:55 Warm up: mirroring an alien

12:00 STRATEGIES FOR EARTH SURVIVAL

Introduce as 'there are people on other planets that have the same problems as you, they also feel sad and angry at times and have sick people in their families. What would you say to them?

In small groups discuss strategies for them and that you may use as well. Ask what they are allowed to do at home

Designate a scribe

Small groups report to the big group. Workers to write up for group to take home next week

12:20 Pillow Jumping

Ask to leave spaceship until next week. Check photographs have been taken. If you want, bring items for big space ship decoration

### ***DAY TWO – Space Station***

9:15 Blast Off

FST to meet parents and ask permission for children to swap phone numbers and addresses. Children to go to playground. Name tags for new children

9:30 Introduction and Welcome Back

If there are any new children ask last week's group to explain what happened last week

Name game: what's your name and what do you like (in a circle, naming others in the circle up to your own name)

9:40 Preparing for Space Travel. Loosen up activities

10:00 Symbol Work: Tell a Story - 3 small groups

Explain to an alien about your family and teach them about how you manage  
Encourage the others to listen to the other stories and those who are distracted can draw symbols or the message/feeling behind them. If time allows, encourage remaining children to draw their symbols/feelings. Facilitators to gestalt a particular symbol eg: lets imagine you're this ... (symbol) what does it feel like, look, smell, noise it makes etc. Follow gestalt exercise sheet

Children who finish early can colour-in space pictures within the group  
Facilitators to monitor other groups in case assistance is required due to facilitator being tied up with one child

- 11:00 BREAK (Rations)
- 11:20 Visit to the Technicoloured Universe  
Explore emotions and what helps to express and integrate emotions  
Use the question sheet to explore the emotions in small groups
- 11:35 Astronauts and Rockets Game - 3 small groups for game  
Hand out strategies sheet in large group and see if there are any additions to be made
- 12:00 Spaceship Launch (everyone) - Making our large spaceship
- 12:20 Cleaning up the Space Station (everyone) - saying goodbye (3 captains), star gifts and swapping I.D. cards

## **CONCLUSION**

The Family Support Team at Very Special Kids are responding to the expressed needs of a very specific group of children. We do not claim to be expert in this field of work, but feedback has been positive from both the children and their parents to date. The programs are new and evolving and we welcome the opportunity to share them with you and to receive comments on any aspects of our work with siblings.

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Additional material contributed by the members of the Family Support Team at Very Special Kids Inc.

‘If there is anything that we wish to change in the child, we should first examine it and see whether it is not something that could be better changed in OURSELVES.’

C J Jung  
Man and His Symbols – USA 1964.