

Family Guidelines: Aftercare



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INTRODUCTION TO FAMILY GUIDELINES

You and your child have been living with heart problems for a long time. Things may change now that he/she has returned home from the hospital, is feeling better and in time has more energy to play, join friends, go to school, and do more around the house, depending on his/her age. You may find that your child needs less attention from you, can do more things for himself or herself, or more often wants to be with others. Families often find this hard to get used to. You may worry about him/her as you always have. Your child in time may be able to do more for himself or herself and may need your help less and less.

We hope the following Family Guidelines will help make things run more smoothly at home and at school. Please read them over with your family and see how they can help you and your child adjust to life after surgery. They may help you to support your child as he/she becomes healthier and more active. You may worry less and find more time for yourself and others to enjoy family events and life experiences.

FAMILY STRESSORS IN TIME OF ACUTE ILLNESS

- -Reduced family organization
- -Less emotional stability
- -More worries
- -Less self-confidence
- -More frustration
- -Difficulty in trusting medical staff
- -Overcompliance with doctors and others

LONG TERM STRESSES ON FAMILY

- -Illness dominates family life
- -Social support fades
- -Parents' work is disrupted
- -Other children feel left out and guilty for wanting attention
- -Spousal partners feel ignored
- -Family structure is challenged



WHAT CAN BE DONE

- -Help families to increase stability and predictability
- -Increase families' knowledge about heart disease and their child's condition
- -Talk about potential behavioral issues that can arise
- -Reduce stress with information and guidance around expectations and behavior (Family Guidelines)

BEFORE WE BEGIN...

You may see these changes in your child:

- Energy
- Height
- Weight
- General growth
- Activity
- Need for rest and sleep
- Muscle strength

You may need to help your child in the following areas:

- Mealtime
- Bedtime
- Medications
- Building strength
- School homework
- Good behavior
- Discipline and rules
- Exercise or physical therapy

**1. LOWER EXPECTATIONS JUST FOR NOW.
Use your own measure.**



2. TAKE CARE OF YOURSELF.
Parents and other family members
have needs too.



3. GO SLOW.

Recovery takes time. Rest is important.



**4. GIVE MEDICATIONS TO YOUR CHILD
AS THE DOCTOR ADVISED.
Call if necessary.**



5. KEEP IT COOL.

You did not cause the illness. You can help your child by staying calm if he/she gets upset.



6. SET LIMITS.

Your child needs to know what the rules are.



7. KEEP IT SIMPLE AND POSITIVE.
Be clear, calm and positive.

**You're doing
great!**



**8. SOLVE PROBLEMS STEP BY STEP.
Make changes one step at a time.**



**9. KEEP THE ILLNESS IN ITS PLACE.
Keep the routines going in the family.**



10. KEEP A RECORD OF YOUR CHILD'S ROUTINES.

Use a notebook to track progress.



REVIEW

1. **LOWER EXPECTATIONS JUST FOR NOW.** Use your own measure.
2. **TAKE CARE OF YOURSELF.** Parents and other family members have needs too.
3. **GO SLOW.** Recovery takes time. Rest is important.
4. **GIVE MEDICATIONS TO YOUR CHILD AS THE DOCTOR ADVISED.** Call if necessary.
5. **KEEP IT COOL.** You did not cause the illness.
You can help your child by staying calm if he/she gets upset.
6. **SET LIMITS.** Your child needs to know what the rules are.
7. **KEEP IT SIMPLE AND POSITIVE.** Be clear, calm and positive.
8. **SOLVE PROBLEMS STEP BY STEP.** Make changes one step at a time.
9. **KEEP THE ILLNESS IN ITS PLACE.** Keep the routines going in the family.
10. **KEEP A RECORD OF YOUR CHILD'S ROUTINES.** Use a notebook to track progress.

REFERENCES

Dr. William McFarlane MD, Professor of Psychiatry, University of Vermont, Maine Medical Center, Spring Harbor Hospital, and formerly of the Psychiatric Institute of New York: Multi-Family Psychoeducational Group Process

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