



Coping Strategies and Expectations

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Welcome to Holland



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Diagnosis

- Devastated
- Catastrophic
- State of panic
- Unbelievable
- World torn apart
- Changes to prior
 - Hopes
 - Plans
 - Expectations
 - Over Time realistic hopes and expectations can be restored.

“Normal” responses to diagnosis

- Uncertainty
- Pressure to explain complex information to family and friends
- Perceived lack of control over your child
- Lack of confidence in your abilities
- Loneliness and isolation
- Fear and anxiety
- Sadness and depression
- Shock and disbelief
- Blame and guilt
- Anger
- Why us?
- Validation
- Relationships are tested

You are Super Stars



And Resilient

The importance of how you view your child

Is my sick child
healthy?

or

Is my
healthy child sick?

Parenting Styles

- Impact of diagnosis
- Impact on your confidence as a parent
- Being able to be firm with a child who already has additional difficulties due to Fanconi Anaemia

Don't forget!

- **ALL** children will show some behaviours that challenges parents at times.
- It is natural for children to want their own way
- It is natural for children to want nice things to happen and continue to happen
- **ALL** children want to avoid doing things that they consider to be unpleasant or inconvenient
- Your job as a parent includes providing nurture, nourishment, safety and promoting development



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Top Ten Parenting Techniques



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1- avoid unnecessary confrontations

Age Range: especially good for pre school

Save it for when it matters – if they want to wear their wellies and its hot, why not? You don't need to control everything, so better to save the effort for the important things you do need to control

2- distract and divert attention

Age range: especially good for pre school children

Very good with young children – when you sense a battle building, quickly point out something interesting and head off any approaching conflict

3- use clear expectations

Age range: good technique for all ages

Don't ask a question if you want compliance. We often ask a question when we aren't really giving an option. For example you might say "Would you like to take your tablet now?" What you actually mean is "It is time to take your tablet now". Make your intention clear and whenever possible say it in a positive way

4- ignore tantrums whenever you can

Age range: especially for early childhood but also good for teenagers

Tantrums are intended to get your attention. If you give it (even negative attention) they will get louder and be used more frequently; let them fizzle out by ignoring them whenever you can

5- cut down on commands

Age range: ALL

Try and notice how often you tell your child what to do compared to how much time you spend in a 2 way conversation. Use “descriptive commentary” where you describe or comment on what they are doing (and you want to see more of); try and use positive comments if possible

6 – decrease the number of times you say “no”

Age range: ALL

Tell your child what would be better to do instead of saying “no”. For example rather than saying “no you can’t play on the i pad” try saying “when you’ve done your homework , then you can have some time on the i pad”

7 – attend to what you want to see not what you don't

Age range: ALL

Parents often notice their child more often when they are doing something they shouldn't be doing rather than when they are doing something they want them to do. Children thrive on ANY attention – positive or negative! Try and let your child know when you have noticed they are doing something you like or approve of – it will happen more often!

8- use praise

Age range: Older children and teenagers

No one likes to be criticised. If you want to encourage your child to do something well, praise any attempt they make even if it is far from perfect

9 – set limits and boundaries

Age range: ALL

A boundary is letting your child know what is acceptable and what is not. Boundaries give children a sense of security and that you are looking out for them, young children especially need parental guidance and to be told when enough is enough.

If you make a boundary stick to it!

10 – be consistent

Age range: ALL

If you set a limit or a consequence stick to it. Children of all ages quickly realise when they can argue or tantrum their way out of a consequence. Try not to set limits on things you can never follow through on.

Managing others curiosity

In order to help build your child's confidence it may be helpful to find a way to respond to other peoples questions or comments when you are out and about..

How you manage this is likely to be dependent on how you have resolved your feelings about the diagnosis of FA

If you recognise that you need support, you will be in a much better place to manage the questions which in turn will inadvertently help your child

Building Your Child's Self - esteem

- If your child feels good about themselves and recognises their own skills and strengths, this will be a protective factor for the times when they face challenges

Self esteem Top Tips

Encourage your child to develop skills in an area that interests them and where there is potential for them to participate and enjoy themselves.

Help your child by noticing when they do something well and support them in making progress with it.

Praise them for the effort they put in rather than the end result

Tell other people about what they are doing well so that it can be celebrated

Problem solving approach

It is a helpful life skill to accept you have to make mistakes in order to learn from them.

Take on the role of coach and rather than telling children how they have done something wrong and what they should have done ask them to tell you what happened and ask:

How do you think it went / What went well / Is there anything you wish you did differently? / What would help you next time to do it that way? / How can I help?

Caring for Siblings

Caring for a child with FA usually involves additional demands on your resources – emotional and practical.

All siblings will have slightly different needs

It can be particularly difficult to juggle responding to the needs of your well child(ren) when the needs of your child with FA sometimes have to take priority

Younger children

Challenges:

Miss your physical presence

Harder to understand time scales

Solutions:

Try to keep routines

Regular substitute carers

Use visual calendars

Sharing out attention

- Have regular play sessions focussed on your well child – something they have chosen
- A few minutes each day or longer sessions a couple of times a week
- Its not the length of time that it important , it is having the focus on them and making it “their” time to choose what to do
- Initially they may find it hard to end the session but once you it becomes regular they will get used to the idea of “their time” and will look forward to it

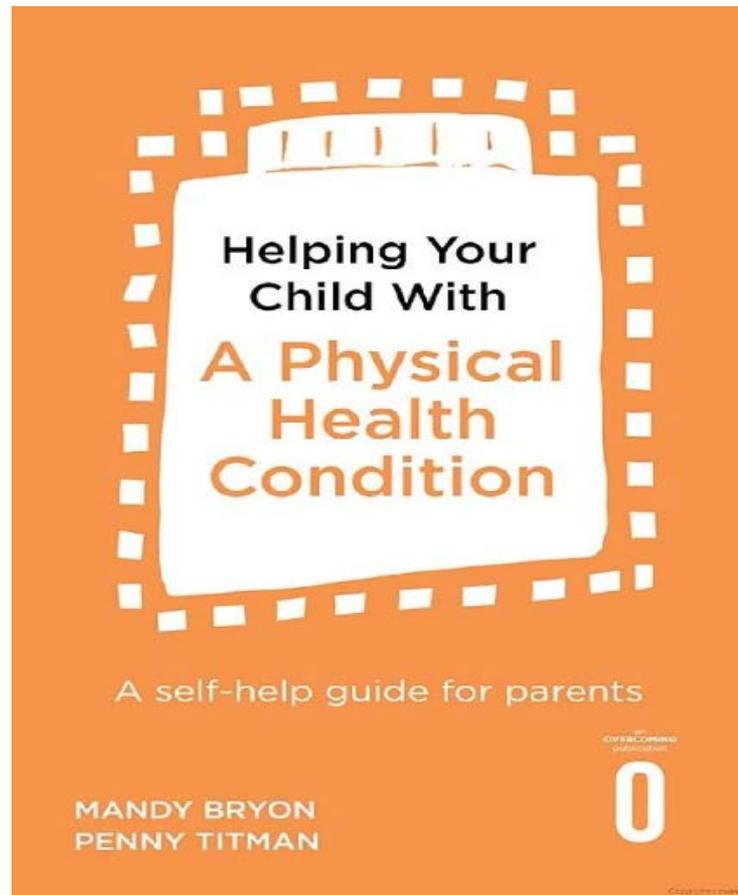
Older children – staying in touch

They may be able to manage without you there physically temporarily but they will miss your attention and interest as they want to share their world with you.

Find ways of keeping each other updated – a family whatsapp group, facetime

Set reminders on your phone to text / call your teenager – they may not respond but they will know you are thinking of them

Reference



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<https://www.bbc.co.uk/iplayer/episode/b08wn37x/hey-duggee-series-2-25-the-going-slow-badge>