MAKING MEMORIES
When your child is very sick it can be hard to imagine, “Making Memories”.

On top of everything else, you are told to make special times. Usually memories just are there.

Finding what you need:
As well as the scroll bar on the side and the standard pdf navigation you can use the buttons on the top of the page to jump to a section and the buttons on the bottom to move from page to page.
• Take photos. With digital cameras and phones, you can take hundreds, thousands, nice ones, silly ones, smiley ones, sad ones, happy ones.

• Professional photo shoot. It can be nice to have good quality photos of the family at any time.

• Video. You will never have enough footage of your child/children. As with photos, have footage of the all the family interacting.

• Make sure YOU AND your partner are included. Get family members/nurses, friends to take photos and video with all the family. Include other children too. Get everyone in as often as you can.

Sometimes, you have to make things happen, so that you can have extra special memories. Like What?

MAKING MEMORIES...
• Box mementoes. Place special ‘whatevers’ in one box. Get bigger boxes, you can be more discerning later about what to keep. Sometimes it’s hospital bands, little shoes, toys they liked but no longer play with, things/cards, special presents. The list is as endless as your imagination. Try not to hoard everything though.

• Hand and foot prints. This can seem a bit too much trouble, but try. Paint your child’s hands and feet and place them on a page or canvas. There are professionals who do this with clay prints for jewellery etc. The simple, home-made paint ones are just as nice. Family members can help with this to make it a fun activity.

• Bucket list. This can be either a wonderful idea or one that causes stress. Maybe make a short list. If it’s done, great - then make another one. Don’t make it a chore. Something as simple as – I want to paint my child’s nails or have a bath/swim with them.

• Make it simple. You might want to take your child to the beach – and the beach just isn’t possible. Clever family/friends might bring the beach to them. A rug with a bucket and spade, a picnic, sunglasses etc, (some sand even).

• If baking or cooking, let your child’s hands through the flour, if this is possible. It might make a mess but it gives them a sense of touch. Let them smell the chocolate, (even if they can’t taste it), hold an egg. All special and messy. Add to this. Let them touch and engage even a little, no matter what their age or ability.
• Some silly family member in a costume; can be Disneyland, in your living room/ward. It doesn’t have to be huge gestures, to make special memories.

• Include your child in their own way in everyday activities. Even though your child is unwell, try to find something in each activity they can do and ignore for now, what they can’t do. Play with them. Make fun in the weirdest things. It’s allowed.

• Talk with, and to your child. Even if your child is not able to talk, or even hear, this does not mean you won’t need to talk. Saying what’s happening, how you feel about them, who is there; these are all special to remember.

• Read to your child. Even if they seem unresponsive or not engaged. Stories can transport you anywhere together. Be as silly as you like when you read.

• Sometimes playing ‘pretend’ is as good as the real thing. All go on a bear hunt, into the jungle, have princess days, teddy bear tea parties. Go for it! Don’t worry about props or materials, as it is more work. Use your imaginations. (Even if your child seems unresponsive, try it.)

• Sing to them, with them, for them. Or play music. The books, songs and music will all conjure up, really special times.

• Teddies. Even if your child isn’t a teddy fan - place teddies with your child often. Teddies are great to cuddle, even if it’s you, that’s the big kid. They are great mementoes.
• Trips out. Try. (Even if it is just around the grounds/garden.) Get help to go. Don’t place too much emphasis on it having to be the best day. Success could be that you got to the place and back.

• Coffee mornings, trips to meet with other families. Get support by making friends and memories all in one. (Go to canteens or grounds in hospital/hospice/respite).

• Diaries. Even if it is just an odd sentence now and again.

• Letters. Writing to your child at various stages, sometimes triggers those little remembrances. Keep them, float them away in bottles, fly them in kites or lanterns, place them somewhere safe. Add to them, read them or just leave them.

• Scrap book. Placing things in a fancy, coherent order can be daunting. Don’t put pressure on yourself. Keep things, until you are able.

• Include family. The whole ‘making memories business’, could be something the family could help with. Ask for family/nurses to help and come up with ideas. Explain what is possible. Put someone in charge of the camera, the activity, the making of the scrapbook, printing the photos. People do feel honoured.
• Special places. Maybe have a special place in a garden, park or location that you might visit easily together (if possible). Your special place together. It doesn’t need to be particular beautiful. It’s your place - that’s all.

• Special times. Make time for just you and your child. Have some ‘us’ time at a specific time of the day, week or month. You may have to make time. Give your partner their own private time too. It doesn’t have to be a long time. If you miss it, make another soon.

• If your child is able, encourage them to decide what they wish to do. Make A Wish organisations can make dreams come true. Ask other children in the family what they would like to do with their sibling. Adapting the activity might be necessary, but their ideas will be wonderful.

• If your child is older and more able, they will most probably have firm ideas of what they wish to do. There may have to be compromises and a little ‘letting go of control’ on your part. Try to be encouraging and join in (if they let you).

• Symbols. Sometimes people associate their child with a symbol. A bear hug, rubbing nose, butterflies, rainbows, a bike, a pet name, a colour, a flower, a white feather etc. Sometimes you pick one, sometimes the child might, sometimes it just happens. For some it can be comforting to see the symbol.
- Cuddles, Holding & Kissing. Seep in as much of your child’s features, smell, cuddles as you can every day. Hold their hand. The best memories can be easy to make.

- If you can share what you do with others then they can share in your memories, now and later.

- For memories to happen, you need to be open to them. You can just try to simply let memories be made - all by themselves.

This is what some families have done. It’s a guide, a starting point if you need it.

Just because someone says, you should “make memories”, remember:

YOU DO MAKE YOUR OWN SPECIAL MEMORIES EVERY DAY.
YOU ARE NOT ALONE

WE ARE NOT MEDICAL PROFESSIONALS, JUST PARENTS.

Click below for more information online

Written by Sharon Thompson
With advice from The Mothers of The Extra Special Kids Ireland Facebook page.
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