THINGS WE WISH WE KNEW

WHEN WE WERE TOLD OUR VICTORIA WAS LIFE LIMITED

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TREAT THIS BOOKLET LIKE A TOOL KIT.

Some tools you may need right now.
Many you might never need.
The rest of the tools are here if you need them.

We don't know it all and this leaflet will not tell you everything, but remember, you are not alone. When we were told the worst news of our lives, we felt so alone. There are people to help you. No one knows exactly how you feel but don't give up.

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.

WHAT IS THIS DOCUMENT ABOUT?

Our daughter Victoria developed a rare condition. At five months she was diagnosed and our world ended. Since then we attempt to help where we can by sharing Victoria's life story and journey. Victoria leads the way as always and this document is what she taught us along the way. It may or may not apply to you and your situation - but as the title says - it contains things that 'We wish we knew' from the very start.

We do not represent anyone other than ourselves and Victoria.

This information is also on the Palliative Hub - Children & Young People website. To visit the site please click Here.

DEALING WITH MEDICAL PROFESSIONALS.

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DEALING WITH MEDICAL PROFESSIONALS.

- Admit to yourself that your child is very ill, even if they don't look it. This is not easy.

- Try to come to terms with some of the information. Don't give up.

- You are not alone. There will be people somewhere who can help.

- Professionals do want to help. They find it hard to say, 'I don't know.' They may seem aloof and uncaring sometimes but most are wonderful and want to help you.

- Getting the professionals to listen sometimes can be difficult. Don't feel like you are 'wasting their time'. Make them wait a few minutes longer until you gather yourself and explain things to them. Try these tips: get someone to go with you to write down what the person says. Request that they spell the word out to you. Write down your questions.

- Keep a notebook with all relevant information between appointments too. Remember this is your child not theirs. Stand quietly and strong. Ask them not to rush you. Explain that you are tired, confused and broken hearted.

- Before you meet a health care professional for an appointment you may like to – Make a list on a note pad or phone of all you want to ask or say. Go through the list with the nurses if you can - ask them to help you make a quick list. You may feel empowered and somewhat prepared if you do this. You also remember things.

- Video behaviour or symptoms that you find hard to explain. Try and have it ready just to play to the doctor when they arrive. Usually your child will not be displaying them when the doctor appears!

DEALING WITH MEDICAL PROFESSIONALS.

- Ask any question you feel you need answered. It is not a silly question if you need an answer.

- This is all new to you. Even if it is not, you are not stupid. You need to know what things mean. Get them to explain in smaller words.

- They may prefer to side step questions. If they do - write them down on the list to ask them again tomorrow.

- Keep small talk to a minimum as it eats into the time doctors/medical teams spend with you.

- Be polite but get to the point. Be nice but firm. Be at eye level. Stand if they are standing. Sit if they are.

- Doctors/hospital personnel have very limited time. Invite them to see you last on the rounds if you feel that you delay them.

- Request if you can Skype or email them, if you are at home with your child, this might save time and energy for all.

- Ask when you can expect to see them or another doctor again. You might not want to miss them (when you step out for a brief minute to go to the loo!)

- Try to make one document/piece of paper which outlines your child's main care needs, medications, likes, dislikes, issues etc. Although these change you may be able to have the main ones ready to hand to any new staff member who is not familiar with your child. This saves you repeating yourself constantly. A 'hospital passport' as it were - where all the main information is there for them in black and white. You could keep this in your notebook or attached to your child's chart in hospital.

- There may be 'teams' of people coming to see you. If it is intimidating for you, say that it is. Explain you are a shy, tired/ emotional person and you prefer one to one chats.

DEALING WITH MEDICAL PROFESSIONALS.

- If your child is very ill call for a nurse/family member to stand in for a few brief minutes so that you can hear the doctor. Try to arrange nursing care for your child if they are at home and attend appointments without them. You can concentrate better this way.

- If you don't know what someone does, what their role is and how they help your child, ask.

- You cannot know everything. Enquire about other professionals you think you may need to see and when they are coming?

- Be appreciative of people's time and patience but remember too – it is their job.

- On a Friday, try to establish a plan of action for the weekend. Make enquires about what happens at weekends if you need certain assistance. Parents can find solutions themselves. 'Googling' is dangerous sometimes and acknowledge that some online information is not always correct. There can be help out there in social media and charity sites. Email if you prefer, someone will know somewhere that can inform you.

- Don't worry about bothering people. Request for doctors to communicate with each other and with people who specialise in your child's condition. Give them the links and emails, if they are willing. Explain perhaps they cannot know everything and you have found this information that could assist them. If they think it is not good, don't apologise or feel defeated. You are doing your best. Give them more information if you find more. They would do this too if it were their child.

- Doctors will not openly disagree with each other. Nurses also will not be able to disagree often with a doctor. This does not mean you can't disagree. Sometimes you may have to listen but you don't always have to agree. Professionals don't always get it right, but ask for further dialogue.

DEALING WITH MEDICAL PROFESSIONALS.

- Request a second option, a second opinion. Ask for time if you need to decide things. To buy you time, say you need to discuss it with your partner/family. If it is important to you and your child - it is important!

- Sometimes saying NO to things or enquiring about more information is scary. You are not being troublesome. It is looking out for your child.

- If you have a teenager try and be the link for them to everyone. A bridge for them – it is not easy but respect their wishes and needs. Their development continues and they want to be the boss.

- You may be assigned a key worker. This means they are your link to others and a person you go to for help, advice and support. Get them to make a care plan with you. This is a document that outlines your plans for the future care of your child. Resuscitation issues, ideal care setting, general hopes etc. This document may change but can help you to make plans together with the professionals.

> IF IT IS IMPORTANT TO YOU AND YOUR CHILD - IT IS IMPORTANT!

DON'T FORGET YOU. YOUR CHILD NEEDS A STRONG YOU.

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DON'T FORGET YOU.

- You are stronger than you ever imagined. To stay strong you need to look after yourself.

- Try to rest. I know this sound impossible, but do. You need your energy for your child. Ask someone else to be there or stay overnight for you, even if it is for just one night. Try to do this often. Sleep is precious!

- If you are given respite hours at home do take it! Try and develop a trust with the carer and get to know her/ him well.

- Look for help, it is valuable. Understand that staff are caring for your child but in the ordinary context they may not be your FRIEND. There are professional boundaries which must protect you and them. This can be very hard to understand as you depend on them but it is for the best. Consider this when using social media. They may be friendly and caring but they must remain 'professional'.

- Trust the staff to care for your child without you. This is hard to do, but they need get to know what your child's nursing care needs are, as they have had to 'deal' with it too. Trust that they will not leave your child in distress. In hospital / hospice ask a mother/parent nearby to keep an eye on things for you, if you feel very uncertain. Give them your number and vice versa. A reassuring text / phone call is very helpful.

- Call the ward/hospice as you need to check for yourself. They won't mind an odd call.

- Every day is a new day. If yesterday was bad, today will probably be better. Don't linger over what you should have done yesterday. Move forward today.

- Your child is in the here and now. Make the most of seeing their beautiful face. Get strength from them too.

- Sometimes there are no answers. Don't give up looking for answers but try to accept some days answers are scarce. Never give up and keep hope alive.

- Try and be a normal family (such as it is). Try to make some fun as hard as that sounds; it is possible.

- Even though your child is sick or unwell, take photos and videos for your family, when you can. Make memory boxes, diaries and anything that will help you remember where you both have been together. Even if you don't want to right now; try to take photos and videos often. Try to see the positives rather than the negatives.

- If caring for your child at home have a bag packed for emergencies. In the bag place all that your child might need for a quick flit to the hospital. Things like extra clothes for you both, towel, toys, copy of 'hospital passport'(list of your child's main care needs), your notebook or a spare one, toiletries, whatever you think you would miss if you needed an overnight stay away from home. This will save you rushing all over the place and being stressed later. You might never need it, but it is there.

DON’T FORGET YOU.

- Family and people want to help. Let them. Don’t feel you need to do everything. Delegate! If people offer to do things you might not need right now, try to steer them to what you do need. Texting is a good way of ‘dropping’ hints of what might be useful for you. ‘On your way home would you mind collecting x for me instead of doing y please? Thanks.”

- You shouldn’t have to entertain people if your child is not well. Get them to make their own tea, even if the kitchen is a mess, they might clean it!

- Do not let visitors sap your energy. Explain to them you need to rest if they call. Get them to run errands for you... pharmacy, nappies, toiletries etc. People do want to help. Take it.

- Ask the nurses/ your partner to help you if you wish people to leave. Make subtle signs to them. It is not being selfish. Your child is more important.

- When people want to help ask them to bring you a healthy snack or nice treat and not to stay too long. When visitors call and you are finally getting a few minutes peace, invite them to come back. Perhaps arrange a time so you can feel more ready. You are not being rude – you are being sensible.

- If people cannot understand your situation, ignore it for now. You can chose your child and family to come first.

- You can keep things private. If it helps you to cope you don’t need to tell nosey Aunt Maggie everything she wants to know.

- Do try to make some time for your own friends. Additionally you will make some of the best connections of your life as you travel this road with your child.

- People don’t want to say the wrong thing. They might say something that hurts but try to forgive them if you can. You may say the wrong thing sometimes too.

- Read, sing, play music, talk, cuddle and kiss your child for as long as you can every day. Even if they seem unresponsive, they may surprise you.

- Talk to other parents. (You might need to consider hospital infections.) Ask them how they cope. Meet with people who are dealing with similar issues. It does help immensely.

- Let it be known that you appreciate people’s concern but can get tired of questions. We found a quick daily/weekly update on Facebook/e-mail a great help. People feel included and you can word it carefully. (Setting up a private page is even better).

- A social worker in a hospital/medical setting has a supportive role. If you hear they may visit, this is a good thing. Their role is to help. Learn the health care professionals’ names. Write them down. If you need help, calling or phoning using someone’s name is effective.

DON'T FORGET YOU.

- Facebook pages and organisations do have support groups; contact them. It is good to communicate and get advice. Also when it is not face to face contact, it is easier sometimes.

- It is ok to be angry, upset and emotional. But …Sometimes you may feel aggressive but watch this. It will not get you anywhere. Be firm but try to stay level headed. Do anything you can to relax and reflect.

- Try not to fight the 'small stuff'. Keep your energy and fight for the big issues. If something annoys you, think - does this really matter right now? Will this affect my child? If it doesn't, let it go. If people help your child, learn to live with it, even if they have annoying ways!

- Think of how your voice sounds. You are a voice for your child.

- Your partner/family is hurting too. Let them help you if they can. If they can't, try to be patient with them until they are ready. Be kind to each other. Try to make time for you both to talk and be together.

- Request professional counselling services, if you need them. This is not showing weakness. If you are stronger you can help your child.

- It is ok to say you cannot cope. Say if things get too much. Ask for help and don't try to do everything and be perfect. This is impossible.

- Take all the help you can get. Don't say you don't need things. You might not need them now - but you may need them later. Family especially need a chance to understand and help.

- Cry when you need to. Sleep when you can, (housework can wait). Always have hope. Your child will always make you smile. Let them love you too. It is ok to smile and be happy.

- Politicians, GPs, Public Health nurses and Social workers can help you to fight for services for your child. Your child deserves the best. Other family members could help you do this. Don't take no for an answer.

- Use respite services. They do wonderful things with your child and care so much. Outside stimulus is good for everyone. You need a break sometimes.

- Think of the future. It might not be the one you had planned but try to curb asking 'how long'. No one knows. It might not be for as long as you planned, it might be for longer than you imagine - but make every day count.

- Remember – Even though this road seems the hardest, longest road right now – You are stronger than you know and You are not alone.

YOU ARE NOT ALONE

WE ARE NOT MEDICAL PROFESSIONALS, JUST PARENTS.

Click below for more information online

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Advice in compiling this was given by; Claire Quinn Head of Ed & Research LauraLynn, and the many dedicated mothers from the private Facebook page Extra Special Kids Ireland.

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