

Compassionate Communication

Engaging with Lived Experience in
Paediatric Palliative Care Research

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Matters of life and death

Compassionate Communication

Engaging with Lived Experience in Paediatric Palliative Care Research

This document offers practical tools to consider how you relate to families who have experienced paediatric palliative care. It offers an exercise in empathy, practical scripts which empower, and a framework for thinking about your language in interactions.



About the Author

Rachel Callander blends art, science and lived experience in her work as a communication consultant in Health, Education and Corporate Industries. Rachel has been part of the Paediatric Palliative Care Centre of Research Excellence since its inception and maintains her connection as an Engagement and Lived Experience Consultant, co-chairing the Community Advisory Board.

Empathy Map

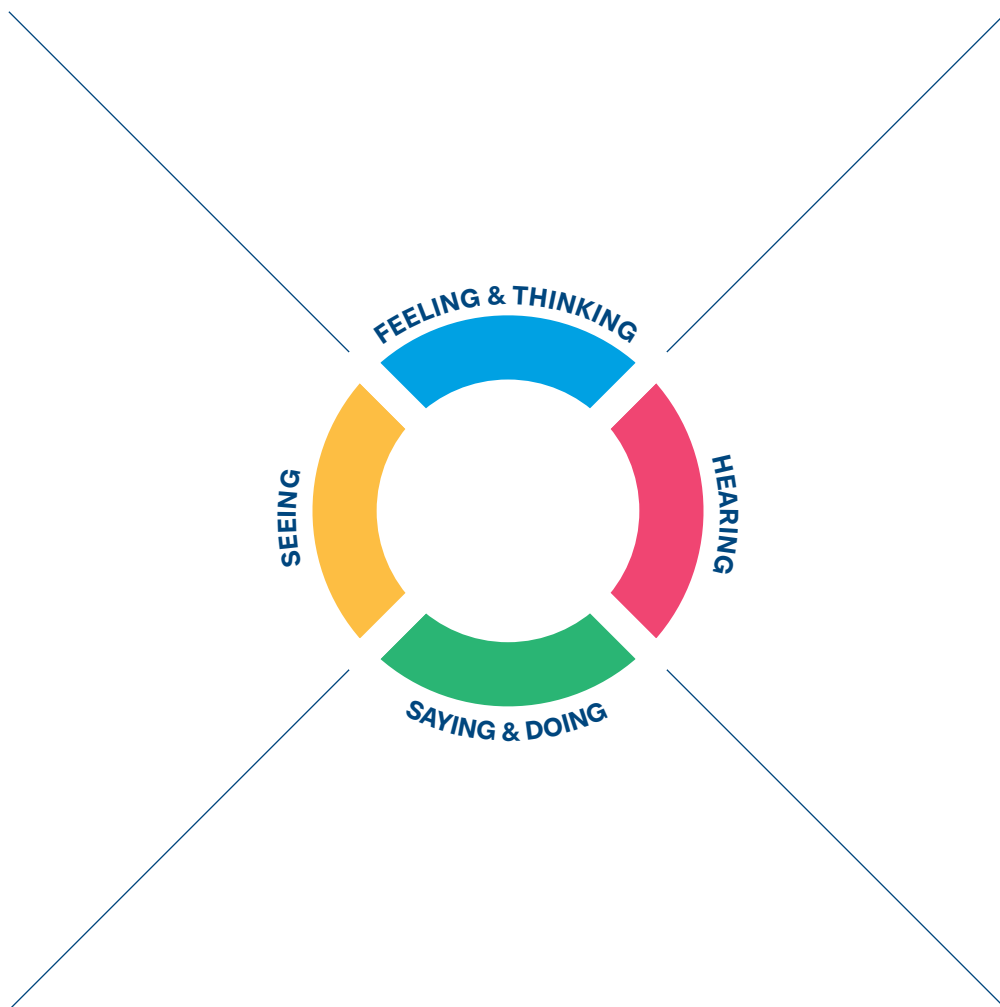
Creating an empathy map can help bring clarity, understanding and compassion to your interactions with those around you.

If we can bring awareness to understand the bigger picture and context that a person is responding from, we are more able to direct care and less likely to react with our own emotions and potentially negative behaviours.

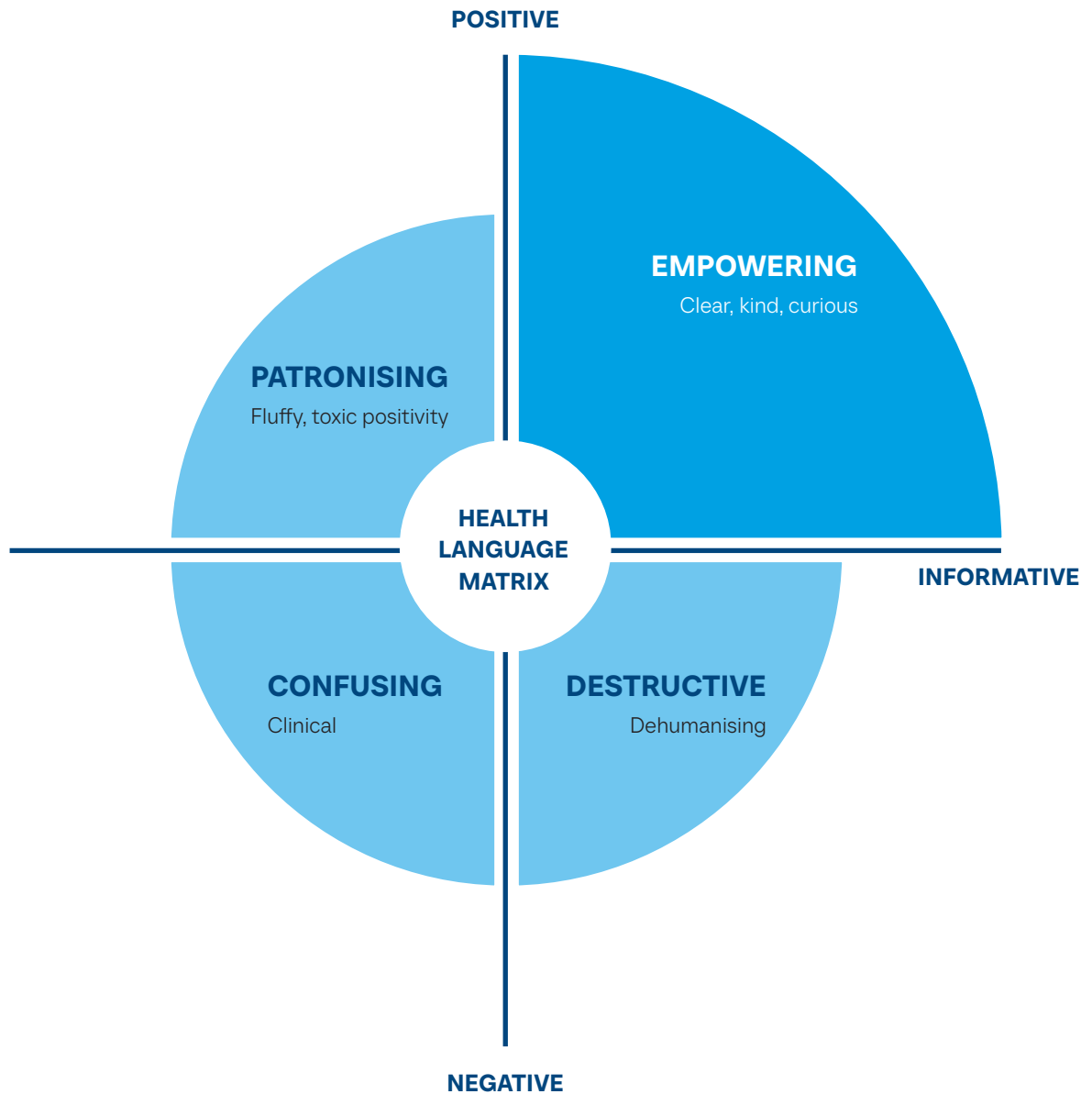
How to create an Empathy Map

Place the name of a person you are working with in the middle of the map. Think deeply into each area of the map and write your responses. Even if we never know for sure what is happening for that person, slowing down and bringing awareness to what could be going on, is a good way to gain insights and perspectives you might not have considered.

You can even put yourself in here, to help you become more aware of what may be driving your own emotions and behaviours.



Health Language Matrix



Patronising

Cliché, fluffy, toxic positivity.

This kind of communication style makes a person feel dismissed, unseen and unheard.

While it comes from a well-meaning and kind space, it doesn't land kind. We fear saying the wrong thing, so we rely on the familiar or cliché as a response to the discomfort we feel in having difficult conversations and being confronted with difficult experiences.

We lean toward positivity as a way of shielding us from the hard reality of a situation, but this can end up being toxic, as it dismisses and minimises the variety of emotions that need to be expressed, acknowledged and held.

Confusing

Wastes time, harms relationships.

You can't move forward when you are confused. It can be a very vulnerable space to be in, and consumers might not feel safe enough to ask for clarification for fear of looking stupid.

Confusion can lead to frustration, which can lead to anger, negative behaviour or withdrawal.

Confused consumers may be wary of experts and specialists and may be slow to trust you. They may resist your suggestions and might appear shut down, labelled "non-compliant", or even "difficult."

You may be working with people who have been in the system for years and who are still grieving their diagnosis or palliative care experience. Be gentle with yourself, and with them.

Being aware of the kind of language and treatment they have already encountered and being able to bring clarity to the information they have been given, is a big part of your work, and ultimately your success.

The research language you speak fluently may not be a language your consumer has learned yet. Help them to understand it. Confusion, will waste time and it can erode the chance to have a positive and collaborative relationship- which ultimately affects the success of the research project.

Destructive

Dehumanising, soul-destroying.

A person understands this kind of language, but it deeply hurts and can cause distress. It adds a layer of pain and grief that is unnecessary. This language can take a person's humanity away and will diminish their potential and ability to see their strengths and uniqueness.

If these words are spoken frequently over a person in their life, they will start to believe that this is what and who they are.

You can't be diagnosed with your identity.

A medical condition or injury will affect how a person experiences their life and world, but they are NOT their condition. This language is rife in healthcare, and we need to bring awareness to it. And to change it.

"I always think of those words and phrases as the scars they've left behind"

- Parent of a child with a rare condition

Empowering

Clear, kind, curious.

Does less talking, more asking.

Reduces assumptions.

Makes the consumer/parent the center of the conversation. Seeks to understand a person's experience of their condition or health needs and seeks how to best care for them.

Connects and clarifies.

Imparts knowledge with compassion.

The quality of questions increases the quality of answers. The more targeted the question, the clearer the response resulting in more accurate delivery of care.

Asking powerful and high-quality questions, and then really listening to the answers is compassion in action. This kind of communication is aligned, it seeks to understand a person and what they need, and it connects us to our shared humanity. Our expertise and knowledge can be delivered and transferred in a way that is meaningful, makes a difference, and minimises conflict.

Health Language Matrix

These lists are examples and thoughts from healthcare professionals and clients/consumers/patients about the different language styles in the language matrix.

Please don't judge or berate yourself if you realise you have used these types of language in your own communication with patients and peers.

Use these examples to bring awareness to your language, so you can adjust and change it where you can, keep a person's humanity intact, and ensure you are explaining things in a way that is understood. Be aware of other examples that are relevant to your field of healthcare.

Patronising

Positive/Jargon

Special kids are only given to special parents.
 It was meant to be.
 It will get easier.
 God only gives you what you can handle.
 You are doing really well for what you have. *(Reducing expectations)*
 Any sentence that begins with At least...
 I don't know how you do it!
 I couldn't do what you do.
 Stay strong.
 Don't worry.
 I know how you feel.
 I know what you are going through.
 You should focus on the positives....
 Your child is in a better place now.
 It was just their time.
 You'll get there in the end.
 At least you don't look sick!
 You can't even tell anything is wrong!
 If I was you, I'd... *(Judgement)*
 It could be worse. *(Minimising)*
 Hang in there.
 Manage.
 My friend's cousin's husband has __ so, I know all about this. *(Making the situation about yourself and what you know to share your own story)*
 They will grow out of it.
 You're fine / Just going through something.
 It's normal.
 I understand what you're feeling.
 You're lucky.
 Don't make a big deal of it.
 He/she lived a full life.
 You can try again.
 It's not as bad as you think.

Confusing

Negative/Jargon

Anything a patient goes home to Google! *(Remember they do this alone, and without any knowledge of whether the info the look up is relevant, correct, or useful – this can add more confusion and more disconnection)*
 Terminology, medical speak, medical terminology. *(Professionals can hide behind this kind of language as an emotional shield to protect them from feeling too much. But it causes more harm to everyone in the long term. This kind of language, until it is understood, is a barrier to connection)*
 Medical jargon.
 Acronyms!
 Percentile ranks, standard deviation, global development delay, developmental delay, significant delay.
 Severity levels, levels in general, non-specific measurements.
 Bilateral.
 Sensorineural.
 Mixed messages from medical professionals. *(You may need to ask what they have been told.)*
 Prognosis.
 Big words – or words that do not usually appear in regular person language. They don't have the be big to be scary.
 Vagueness.
 Information overload – a person can only take in so much information at once, then it is just a blur.
 Assuming patients have a background knowledge of biology and health etc.
 Weight-based dosage.
 Explaining insurance benefits with patients
 Appeal process, time frame.
 Inside language.

Destructive

Negative/Informative

Words with negative connotations.
 Incompatible with life.
 Setting limits on the patient.
 Making assumptions, assuming everyone with the same diagnosis will be the same.
 Referral to what it 'normal' or 'typical.'
 Confined to a wheelchair.
 Suffers from...
 Malformed/malformations, deformity.
 Putting patients in a box – limitations.
 X amount of time to live.
 Downs child, 'downie'.
 Skills deficits.
 Labels.
 Abnormal.
 Spastic.
 Norms.
 Complex.
 Having lower expectations.
 Below average, atypical.
 There's a missing part.
 What do you mean, they can't do that?
 Deficits based,
 Disordered.
 Significant delay.
 Impairment.
 Weakness.
 Retarded.
 Mutated.
 Low functioning.
 Red flags.
 Neurotypical.
 People 'like that'.
 What's wrong?
 Delay *(speech/walking)*
 Comparing kids
 Does your child still walk?
 Email delivery.
 Not allowing space for grief, are you still sad?
 Product of conception – miscarriage.
 We need to clear the debris – miscarriage.

Health Language Matrix

These lists are examples and thoughts from a Paediatric Palliative Care specific training day.

Please don't judge or berate yourself if you realise you have used these words or phrases in your own communication with patients and peers.

Use these examples to bring awareness to your language, so you can adjust and change it where you can, keep a person's humanity intact, and ensure you are explaining things in a way that is understood. Be aware of other examples that are relevant to your field of healthcare.

Patronising

Positive/Jargon

I couldn't do what you do.
 You're so strong.
 I can't imagine what you're going through.
 They're in a better palace.
 At least they're out of pain.
 They're free now.
 They've gone to God.
 At least you didn't get stretch marks.
 You're young, you can have more children.
 This is better for everyone.
 You need to just relax.
 Bad news sandwich.
 Special kids are only given to special parents.
 Time heals all wounds.
 Just give it time and you'll be OK.
 Your life will be so much easier now.

Confusing

Negative/Jargon

Dr rankings.
 Who is your CNC?
 Treatment stages.
 Generic name/real name.
 Hit on by the 'fellow'.
 You've got a bug in your blood.
 Cat-scan (the child was terrified of cats).
 Equipment information.
 Progression.
 Controlling disease.
 Over medicalising our own discomfort.
 Consultant/specialist/paediatrician – I am all of these things!
 Prem baby = high risk – of what?
 Long overly detailed emails.
 Observation parameters or test results with no explanation (even the words observation parameters is weird for a parent).
 Handovers – talking to other HCP and not consumer.
 Drug names.
 Not explaining what it means, what it is, how it works.
 Hiding behind clinical language and formal words.

Destructive

Negative/Informative

Failure to thrive.
 Brain tumour in bed 2.
 That mum is a b*@\$h!
 Nothing left to be done – we'll call palliative care.
 Withdrawal of care.
 Can't eat.
 No point in feeding or washing them.
 Not viable.
 Ineligible, not eligible.
 Will never....
 Pointless.
 Incompetent.
 Failure to progress.
 Failure to thrive.
 Not a good candidate.
 Cost effective.
 You should have brought them to hospital earlier.
 There's nothing we can do.
 Retained product of conception.
 Geriatric pregnancy or 'gerry preg'.
 Problem lists.
 She's not going to live to see old bones.
 Like a vegetable.
 Ceilings or limits of care.
 Withdraw care.
 % chance.
 Risk language.
 Difficult family.
 Non-compliant family.

Empowering Questions

Questions help us learn more from another, while also helping us to engage compassionately, clearly and curiously. They allow us to direct our knowledge and care in meaningful ways.

These four overarching question themes or banner questions are often too big to be answered and can even be unsafe or triggering. They are a guide, to help us think about how else to ask these big, yet important questions.

Breaking them down into smaller nuanced questions, allows the highest quality of response and relationships to be built. They reduce assumptions and help us understand different perspectives and experiences.

What are you **proud** of?

What do you **hope** for?

What are you **afraid** of?

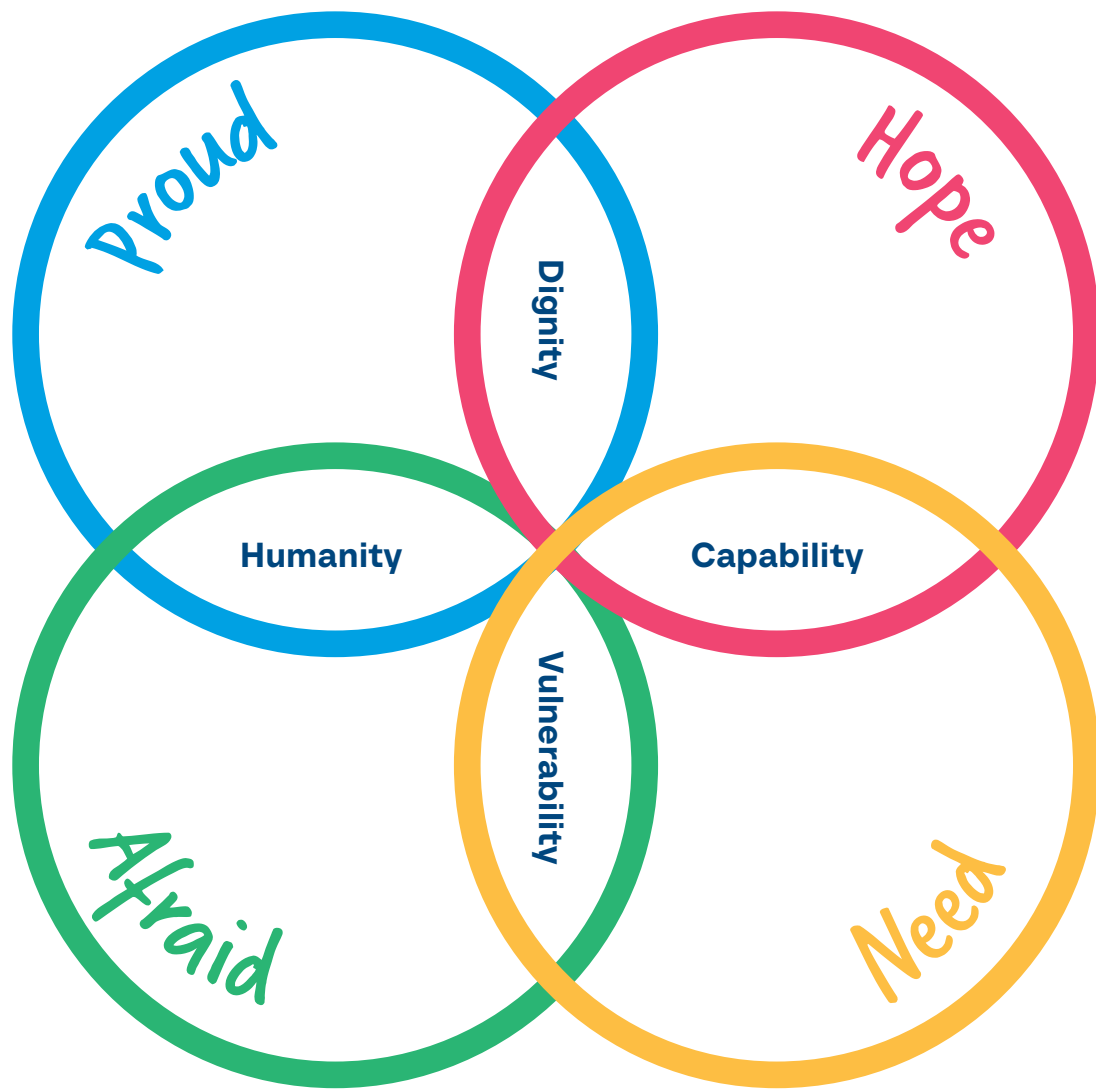
What do you **need**?

The following lists over page are questions that have been created during workshops with healthcare professionals across many specialties.

The healthcare professionals were asked to think of as many ways of asking these four questions, to help them to feel more confident in communicating with their patients and colleagues.

These lists are not exhaustive, and you may want to think of others that are more relevant to you in your work. They serve as a starting point for you as you start to think of ways to have more meaningful and clear conversations.

Read through these lists of questions, identifying any that resonate. Make a note of them and start using them on those around you. It may feel awkward and strange at first. Getting used to new ways of communicating will take time and practice until it feels natural.



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What are you proud of?

What's working for you already?

How does that look?

Can you tell us more about that?

Can we enhance anything about this?

What matters to you?

What's the best part of your life?

What do you enjoy doing?

What pleases you about your child's progress?

What works with your family?

Have you already had a good outcome, and what was it? What made it good for you?

What makes you smile when you think of your child?

What delights you about your child?

What's your favourite thing, or what do you love most about your child?

What makes your child sparkle?

What is something good that happens in your day?

What inspires you?

What are your strengths?

What are some achievements you are proud of?

What is it like to be you?

What makes you feel you are your best you?

What do you love about yourself?

What do you enjoy about yourself?

What matters to you today?

What was the best part of your day?

What's been great about today?

What gives you joy?

What has been a high-five moment today?

What would a high-five moment look like for you?

What are the things that make you feel more alive? When do you feel most alive?

How have you impressed yourself?

Is there something cool that you've been up to? What is cool to you? If you could get up to something cool what would that be?

What's something you've done that you never imagined you would do?

What makes you laugh?

What makes you happy?

What do you enjoy doing?

What has energised you this week?

What do you do well?

What do you do best at school?

What makes you get out of bed in the morning?

What do you love about the person you care for?

What's a memory that brings you joy?

What makes you feel joy?

What are your superpowers?

What do you do best when you are at home?

What excites you?

What has made you smile today?

Has anything happened today that puts a bounce in your step?

What have you done that's brought great joy to you or someone else?

What has made you feel thankful today?

Has anything made you feel grateful today?

What's floating your boat right now?

What good things have you noticed today?

What do you love to do?

What do you love to do together?

What is your experience of life?

What is your experience of your condition?

What are some of the challenges you've overcome?

What are your child's strengths?

What was a win for you or your child this week?

What went well this week? What worked?

We can see how much your child has improved with ___. Is there anything else you can see that they are improving with?

What does a happy moment look like for you/your family?

How do you celebrate your child?

What achievements have you had as a family?

What is something new you/your child has learned?

What is something you feel you have had success with or achieved?

What skills have you learned through being your child's parent?

What do you think your strengths are as a parent?

Can you tell me something you loved about your child?

How did you celebrate your child?

Where have you connected this week?

Was there a moment this week that brought you joy- even a small one?

Did anything make you smile this week?

What do you love?

Is there a memory you have of your child that you love?

What do you **hope** for?

What are your dreams?

What inspires you?

What are your short or long-term goals?

What would quality of life look like for you?

In a week/month/years time, what would you like to be different?

What is your vision for you/your child?

What would you like to achieve?

How can we help you to get there?

What is fun for you?

What would you like more of in your life?

What would you like less of in your life?

What does a good day look like?

What does a bad day look like?

How many good days have you had this week/month?

How many bad days have you had this week/month?

Do you think about the future?

What does it look like for you?

Do you have any aspirations or goals?

If you could change one thing in your life to make it better, what would it be?

What are you looking forward to?

What brings you comfort?

Is there something you've imagined doing but never done?

Can we work towards that?

What is the first step towards this?

Who do you want to be?

How do you want to feel?

What are you feeling good about doing today?

What are you looking forward to celebrating?

What would make you smile?

What is important to you?

How far would you like to get with that this week/month/year?

How would you like to celebrate achieving those things?

What matters most to you?

What would you like tomorrow to look like?

What are you curious about?

When do you feel most free?

What does quality of life look like to you as a family?

What does a good outcome look like to you?

What is your goal? What can I do to help you reach that goal?

What will it look like when it is better?

When you leave today, what is one thing you'd like to have achieved/discussed/put in place/started/finished?

How many good days are you having at the moment? What does a good day look like? Can we help you have more good days?

What would you like tomorrow to look like?

What would make you feel a sense of meaning?

Is there anything you're hoping to get out of this meeting/project/research?

Do you have anything special planned for the holiday/weekend?

What moments do you notice your child is most at peace and comfortable?

How do you think (child's name) would want to spend this time?

What's on your bucket list and can we help make some of those things happen?

What are you afraid of?

What is forefront on your mind?

What is the top priority for you?

Is there anything you are unsure of?

Do you have any hesitations?

What are your biggest challenges?

What are the barriers in your life to achieving your goals?

What is holding you back?

What frustrations are you feeling?

What is concerning you right now?

Are you worried about anything in particular?

What is one concern in the forefront of your mind?

How does this affect the others in your family?

What gives you butterflies in your stomach?

Do you have any fears of what's to come/next steps?

What are your concerns with the process? With the therapy?

What keeps you up at night?

Is there a thought that wakes you up at night?

How do you respond to stress?

What challenges are you facing? Socially, as a family, academically?

Do you have any environmental challenges?

Does this sound possible? If not, what is holding you back from thinking it is?

What is missing?

What are your biggest concerns?

Is there anything you wish you could change about this situation?

What is worrying you the most?

What isn't working for you anymore?

What upsets you the most?

Is there anything you are avoiding?

Is there anything making you anxious?

What questions do you have?

How does this affect your child? Your family?

What doesn't feel right or make sense?

What concerns do you have about your child's/your future?

What do you find challenging?

Is there anything that you have heard/seen/googled that is causing you distress?

What are the most challenging parts of your day?

How can we support you to make those challenges easier?

Do you have any worry clouds?

What has been the most challenging part of your day?

Are there things you don't want to think about?

Is there anything you're avoiding?

What are your coping strategies as a family during challenging times?

Is there anything you can't stop thinking about?

Is there anything that doesn't feel right? What is your gut telling you?

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What do you need?

What would make life easier?
 How can we get you what you need?
 What would good support look and feel like?
 How can I best help you today?
 What do you need to move forward?
 What is the next step?
 What is the most important thing to you? What is your biggest/priority?
 What makes you day harder that it needs to be?
 What one thing could make life better for you?
 Is there anything I can do for you right now?
 How does this impact your life?
 What would really help here?
 Is anything else required?
 How could I connect with you in a more meaningful way?
 How do you feel about today's news?
 What do you need from me to be at your best?
 What can't you live without?
 What would be most helpful in this moment?
 Is it OK to be here with you now?
 What can I do to support you?
 Is there something I can help you to make different?
 Is there anything more I can do for you right now?
 How can I show up big for you?
 What could be done differently?
 Imagine if you had all that you need right now, what would be different?
 What is already working for you?
 How can we enhance the things that are already working for you?
 What help is helpful? What help is unhelpful?
 What makes you feel safe?
 What feeling would you like to reduce in your life?
 Are you struggling with anything?
 Can I provide you with more information?

How can I support you?
 Is there anything hindering you? Are there any roadblocks?
 Who or what will help get you to your next step?
 How can we assist with this process?
 What is missing? What further information do you need? How do you feel about ...?
 What are your thoughts on ...?
 Can you see a way that we can make things easier for you? Can we make things easier for you?
 What is harder than it needs to be?
 What can we explore further with you?
 Are you getting adequate support? Do you feel supported? Is there anything missing?
 What is one thing that would make you/your child's life better/easier?
 What are the hardest things for you as a family?
 How do you think we can support you?
 What supports do you have in place to help your child? What supports do you have to help YOU?
 Do you have questions that need answers?
 Can you think of anything that would make this better for you?
 Are there things that would be useful for you to learn that we can teach you?
 How can we best support you and your family?
 Is there anything you need more information on?
 What have you understood about your child's diagnosis?
 What have you understood about your diagnosis?
 What would be most helpful for you and your family?
 What more can be done to support your family and the goals we have made?

What do you need to flourish?
 Who else needs to be in the team?
 How can we best work together?
 Is there anything that we can learn from you that would make things better?
 Is there anything that we are missing, or not fully understanding about you/your child/your family?
 Are there any barriers to you getting or asking for support?
 What have you been told about your child's diagnosis?
 How do you feel about this?
 Is there anything you are still unsure about relating to your child's diagnosis?
 Does your child's diagnosis carry any additional relevance culturally/religiously to you?
 How can we best support you culturally/religiously?
 What is this like for you as a parent? As a family? How can we support you/your family?
 Is there anything that we are doing that is not working?
 Do we need to change anything?
 How do you think we can change things to make this better?
 Just because we can do certain things (treatment) doesn't mean we should. Is there anything you'd like us to stop?
 How can we advocate for you?
 Do you have any unanswered questions?
 You may not be able to think right now, would it be helpful if I share what other families have found helpful?
 Help me understand what you're feeling/what you mean/what this is like
 What could make a positive difference for you today?

Notes

[illegible]

