EFFECTIVE COMMUNICATION IN HEALTHCARE: *Disability*

BY RACHEL CALLANDER

As a health professional, you are an incredibly important person in the lives of a parent and patient right now.

You have a lot of power and influence. Your words will be clung to, misunderstood, questioned. The information you share will change a patient's life. It introduces a new reality, a new future.

How are you delivering this new reality? Is your communication effective? Empowering? Understood?

Or is unnecessary trauma being added, and your skills and knowledge wasted, because your communication style is breaking down the critical relationship between yourself, and the parent or patient?

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Evie Callander 30.03.2008- 10.10.10
Born with Partial Trisomy 9 and Partial Monosomy 6

THE TRICHOTOMY OF CARE

We need a model of health that ensures everybody - the patient, the parent, and the health professional - is cared for. Effective communication is a vital part of this system.

Basic communication skills alone are not sufficient to establish and sustain a positive relationship between the Patient/Parent and the Health Professional.

A successful relationship requires the ability to share perceptions, feelings, and fears of the medical issue.

It allows goals to be aligned for the outcome of treatment, it identifies support networks, and provides psychological and emotional support.

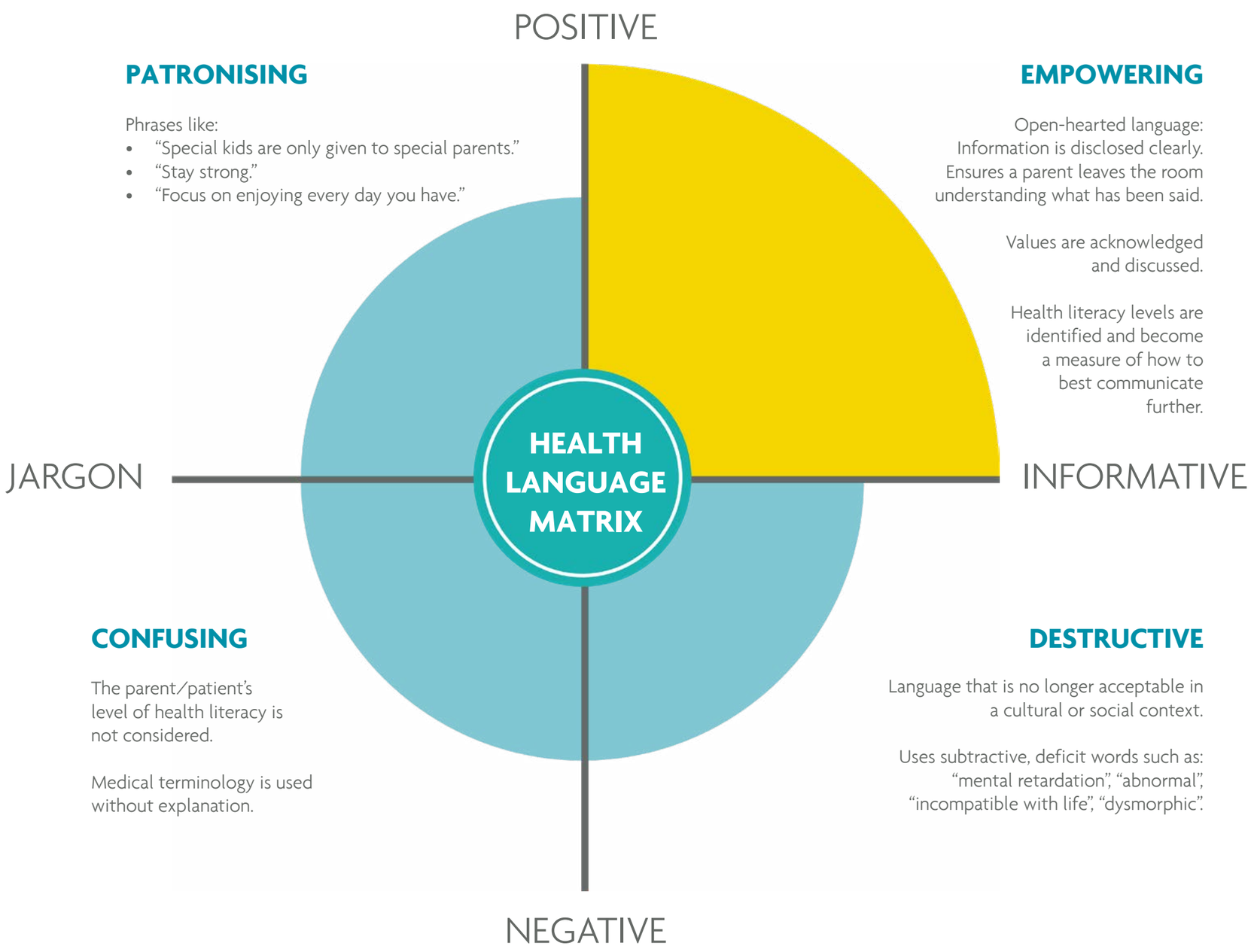
Effective communication transcends basic skills, and integrates both Patient/Parent-centred care, and Professional-centred approaches.

For good relationships to thrive, everybody needs to be cared for. The Patient. The Parent/Carer. The Professional.

"Parents and patients are more trusting of, and committed to, health professionals who adopt an empowering communication style with them."

Robyn Ouschan, Jillian Sweeney, Lester Johnson, (2006) "Customer empowerment and relationship outcomes in healthcare consultations", European Journal of Marketing, Vol. 40 Issue: 9/10, pp.1068-1086,

THE HEALTH LANGUAGE MATRIX



"These are the words we currently use, perhaps mostly because of the medical profession, to describe disability: Retarded. Incompatible with life. Abnormal. Dysfunctional. Dysmorphic. Disabled. Defective. Mutated.

This language takes potential and even ability away from a person.

The words we have associated with "disability" reveal a deficit culture that does not accept, encourage, or enable humanity."

Rachel Callander

WE DEEP DIVE INTO EACH QUADRANT OF THE HEALTH LANGUAGE MATRIX IN THE FOLLOWING PAGES

POSITIVE/ JARGON

PARENT / PATIENT OUTCOME	HEALTH PROFESSIONAL OUTCOME
A sense of frustration, not being seen or heard, not acknowledged or valued.	Disengaged parent/patient.
Feelings of being dismissed and misunderstood.	Little progress in health outcomes.
Time has been wasted.	Parent/patient is uneducated on the medical reality of their condition.
Communication is fluffy and irrelevant, the patient doesn't really know how to progress, or what has even been said.	Frustrated at lack of progress.
	Compassion fatigue sets in as they're trying to communicate with empathy and kindness, but it isn't working, so what's the point.
	Fuels a belief that compassion and kindness are futile in a health setting.

While this kind of communication often comes from a place of kindness, this is not how it is perceived by a parent/patient, and the health professional is at risk of coming across as insensitive, or irrelevant.

A health professional might be trying to look on the bright side of a situation, but a parent/patient might need more time to get to that place if they ever do.

Here is where compassion fatigue can set in.

A health professional may be trying hard to be compassionate, but has not established how the parent/patient would like to be communicated with, so their kindness falls short. This leaves a parent/patient feeling dismissed, and unseen, which causes a breakdown in the relationship because the parent/patient finds the professional to be fluffy, overly hopeful or positive, and therefore difficult to talk to about serious problems.

A health professional may get frustrated at the lack of positive health results despite all the effort and empathy they are putting in and expressing.

NEGATIVE/ JARGON

PARENT / PATIENT OUTCOME	HEALTH PROFESSIONAL OUTCOME
Confusion, mistrust, frustration.	Parent/patient seems uninterested in asking questions, not focused, absent, not listening.
No knowledge of what is happening.	Health outcomes are less optimal, because there is no engagement in the process, so the patient needs to be seen more often.
A sense that time is wasted because the information shared hasn't been understood. This can lead to further explanations that timeframes might not allow for.	Medications and therapies may be used sub-optimally or not at all, resulting in more time in the hospital, more resources used, more costs and time wasted.
The parent/patient feels stupid at not being able to understand, so shuts down and feels small, and fears wasting the time of the professional further.	
Resolves to go home and try Google instead. Alone.	

A few weeks after the birth of my daughter Evie, a paediatrician came in to explain her genetic test results.

He told me that Evie's unbalanced chromosomal translocation involved the short arms of chromosomes 9 and 6. I was sleep deprived, recovering from a Caesarian, and emotionally exhausted. A few days earlier, we had been told that Evie had Edwards Syndrome and would most likely not live more than a few weeks. We were living in the NICU and Evie had undergone so many tests I had lost track of where things were at.

This new doctor was now telling us that Evie did not have Edwards Syndrome, but something else I only briefly heard. It sounded like a foreign language.

I knew he was really busy and I just tried to keep up. I tried to hold on to anything I could understand, to stay grounded. I thought he was telling me that Evie had short arms.

So while he was talking, all I could think about were Evie's arms. I was so confused. To me, Evie's arms looked perfectly long. I was wondering why, on top of everything else that was going in her fragile little body, were they so focused on her arms? Surely her arms were the least of our concerns.

He then used a metaphor for a library to explain things further: Evie's condition had been discovered to come from my own balanced chromosomal translocation, which I had no idea about until this moment.

So now I was thinking about library books, short arms, and the mysterious behaviour of chromosomes, and I had no idea how to make sense of it all.

The Doctor's manner was impersonal and brusque, and I decided that I did not like this man. I felt so stupid when I asked what they were going to do about Evie's arms, and he had to tell me, that no, he meant the arms of the chromosomes. Having no idea what a chromosome even looked like, let alone the length and importance of their arms, I still was none the wiser.

I wanted nothing more to do with this doctor and nothing he said after that, landed. I heard nothing, acted upon nothing, and could not even remember what Evie's diagnosis was called, or how to spell it or tell anyone else about it. I was confused, upset and didn't know what questions to ask.

"We are quick to place value judgements on a person, often before they are even born, before they have a chance to reveal their unique character, before they can enrich our own experience of life."

RACHEL CALLANDER

NEGATIVE/ INFORMATIVE

PARENT / PATIENT OUTCOME

Feelings of emotional fragility.

Drained, soul destroyed, hurt, offended, ostracised, small, a sense of hopelessness and overwhelm.

The parent/patient can feel anger, fear, an inability to cope, intense grief, disconnection.

They can act unpredictably, and become difficult to work with, quick to blame, quick to feel victimised.

Slow to achieve health outcomes.

HEALTH PROFESSIONAL OUTCOME

A parent/patient who is mistrustful, disengaged, quick to anger, frustrated, or completely withdrawn and depressed. Abusive and retaliates by complaining.

The Professional may not even be aware they are fuelling this situation - after all, they are being medically accurate, and have always used this language in the past, so they see no need to change.

The Professional acts out of habit, arrogance, unwilling to change despite the negative reactions from the parent/patient and other staff around them.

Lawsuits against health professionals and hospitals come from this space.

POSITIVE /INFORMATIVE

PARENT / PATIENT OUTCOME	HEALTH PROFESSIONAL OUTCOME
Information is shared with clarity, kindness and in a way that is best understood. This is established by the professional asking how best to explain a medical concept.	A parent/patient fully invested in their health, empowered to look after themselves as much as possible.
Medical information is shared with compassion, and an expectation ofsupport is established and nurtured.	Support networks are established, new skills are taught, the care team is aligned, and less likely to be blamed for a negative outcome because fears and risks have been discussed openly and the relationship is strong.
The Patient, the Parent, and the Professional are all on the same team.	Uncertainties are shared openly and honestly without backlash, fallout or frustration. Information is shared, and problems are solved together.
Everyone responsible for the care of a person is equally involved. All knowledge is shared, the person is the focus, rather than the illness.	All parties' skills are utilised, there is less reliance on one person. The health professional is a source of motivation, incentive, reassurance, and support.
The identity of the person being cared for is valued and protected.	Use of body language, eye contact, acknowledgement, listening. Use of words that are congruent with the patient or parent. Everything that has been said in the room has been understood.
Meaning is forged.	

Research is constantly revealing the power of POSITIVE INFORMATIVE language.

"Doctors with better communication and interpersonal skills are able to detect problems earlier. They are often able to prevent medical crises and expensive intervention, and they provide better support to their patients.

This can lead to higher-quality outcomes and better satisfaction, lower costs of care, greater parent/patient understanding of health issues, and better adherence to the treatment process.

There is currently a greater expectation of collaborative decision making, with physicians and patients participating as partners to achieve the agreed-upon goals and the attainment of quality of life.

There are also benefits for doctors. A study of primary care physicians found that undertaking an intensive education program in mindful communication improved patient outcomes and personal well-being for the doctors.

The medical literature also provides reassuring evidence that an effective patient-centred model does not take more time."

The Oschner Journal 2010 Doctor-Patient Communication: A Review. www.ncbi.nlm.nih.gov/pmc/articles/PMC3096184/




WHAT DOES EMPOWERING AND EFFECTIVE COMMUNICATION LOOK LIKE?

...and how do we measure it?

Studies show that despite the countless models out there to measure the effect and impact of the patient experience on health outcomes, there are still areas that are vague, and information that is biased or missing.

This is especially true around effective communication. The industry has a largely incomplete data set, which has led to unclear guidelines and incomplete strategies for future EC development.

When applying the HEALTH model to measure effective communication, we are granted a much more complete picture, that shows the intrinsic links between communication, and patient/parent/professional health outcomes.

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HOLISTIC

The art and science of healing that is concerned about the whole person, rather than seeing them as a (collection of) failing body part/s. One where we are open to investigating alternative options, discussing belief systems, cultural influences, and listening to the values of the parent/ patient. Agreement on treatment methods is a key factor which influences outcomes.

EMPATHY

Compassion is the practical application of empathy. The Institute of Heathcare Communciation notes that "Research evidence suggests that a clinician's ability to explain, listen and empathise has a profound effect on biological and functional health outcomes as well as parent/ patient satisfaction and experience of care."

ALLIES

United. Connected. Able to collaborate. A sense of being a team.
When these actions are in play in communication, good things can happen.
Resources are used optimally, knowledge is shared and discussed, creativity and innovation can flourish, systems are in flow.

LANGUAGE

First, do no harm. The words and language used by a medical professional at diagnosis have a significant impact on how a parent/patient relates to their health professional, and how they navigate their future. Effective doctor-patient communication can be a source of motivation, incentive, reassurance, and support.

TIME

For a health professional, working under severe time constraints takes its toll. For a parent, seeing multiple specialists, often on multiple days, sitting in waiting rooms with a sick child, also takes a huge toll. If the Parent/Patient perceives their time to be wasted, or of little importance, this will significantly affect their experience of, and relationship with, their health professional.

HOSPITALITY

The Latin root of the word hospital is '**hospes**', and hospitality has the same etymology and genesis. Using empowering communication to facilitate the spirit of hospitality in the hospital/ clinic/room is a foundational part of building the much-needed respect and trust required for strong relationships between parents, patients and professionals.

6 IMPORTANT QUESTIONS

to ask about your current workplace

1. Has your hospital or any of your medical staff been complained against as a result of poor communication?

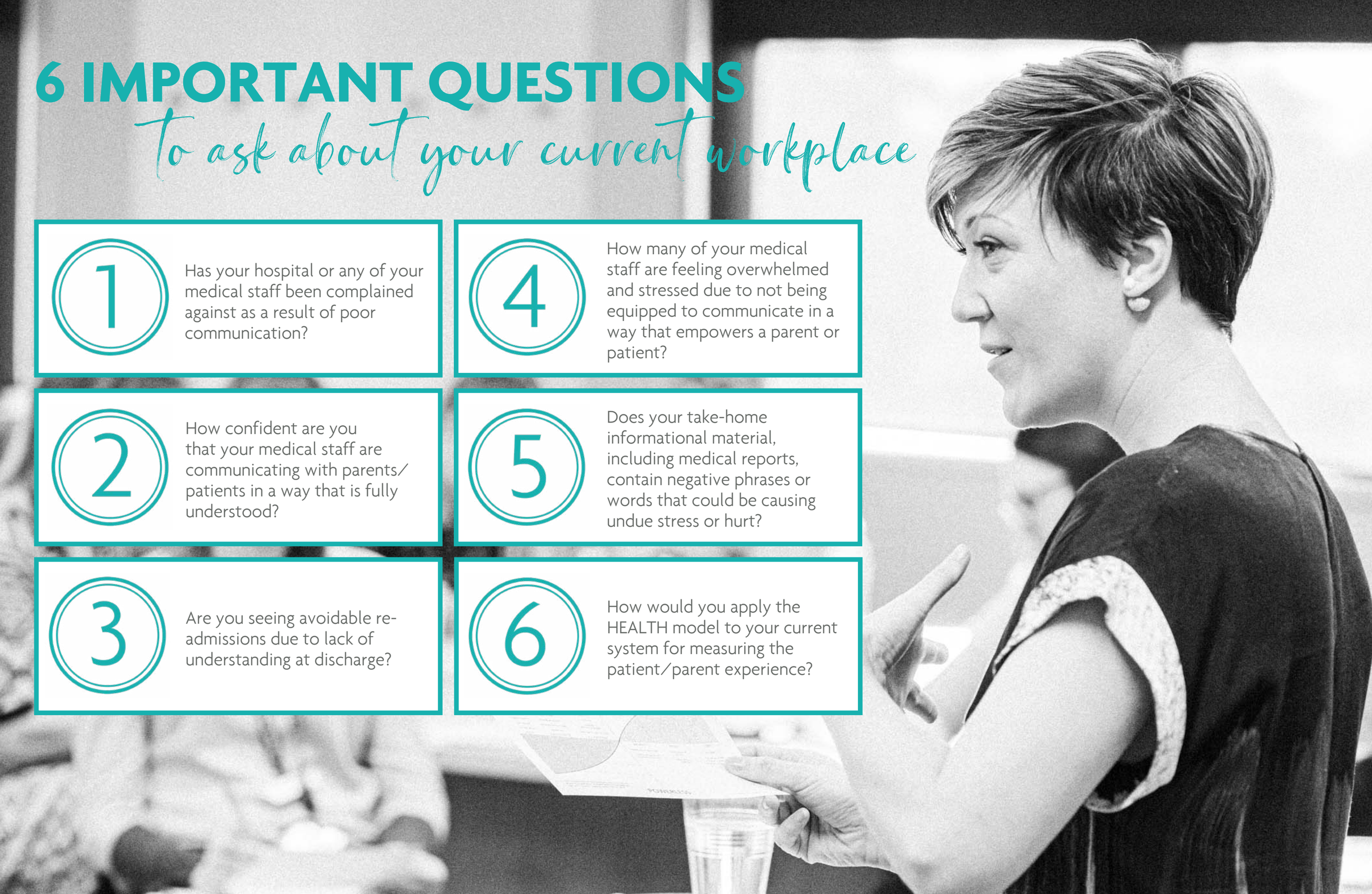
2. How confident are you that your medical staff are communicating with parents/patients in a way that is fully understood?

3. Are you seeing avoidable re-admissions due to lack of understanding at discharge?

4. How many of your medical staff are feeling overwhelmed and stressed due to not being equipped to communicate in a way that empowers a parent or patient?

5. Does your take-home informational material, including medical reports, contain negative phrases or words that could be causing undue stress or hurt?

6. How would you apply the HEALTH model to your current system for measuring the patient/parent experience?



WHAT NEXT?

We offer keynote presentations and ALLYSHIP, a group of 6 workshops that focus on how to implement a HEALTH-y approach to measuring patient/parent and professional satisfaction.

These programs are revolutionising the ways in which health professionals are communicating with patients/parents. They are seeing more positive health outcomes, and are experiencing higher job satisfaction, less stress and burnout, and a more positive culture within their organisations.

We would love to work with you and your team.

"You have revitalised and revolutionised my clinical approach to my patients."

— A/Prof David McDonald, MBBS FRACP DA(UK)

"[Rachel] gave everyone a blueprint to really shift the way in which we, as a rare disease community interact and communicate with the world of healthcare."

— Kendall Davis, Global Genes

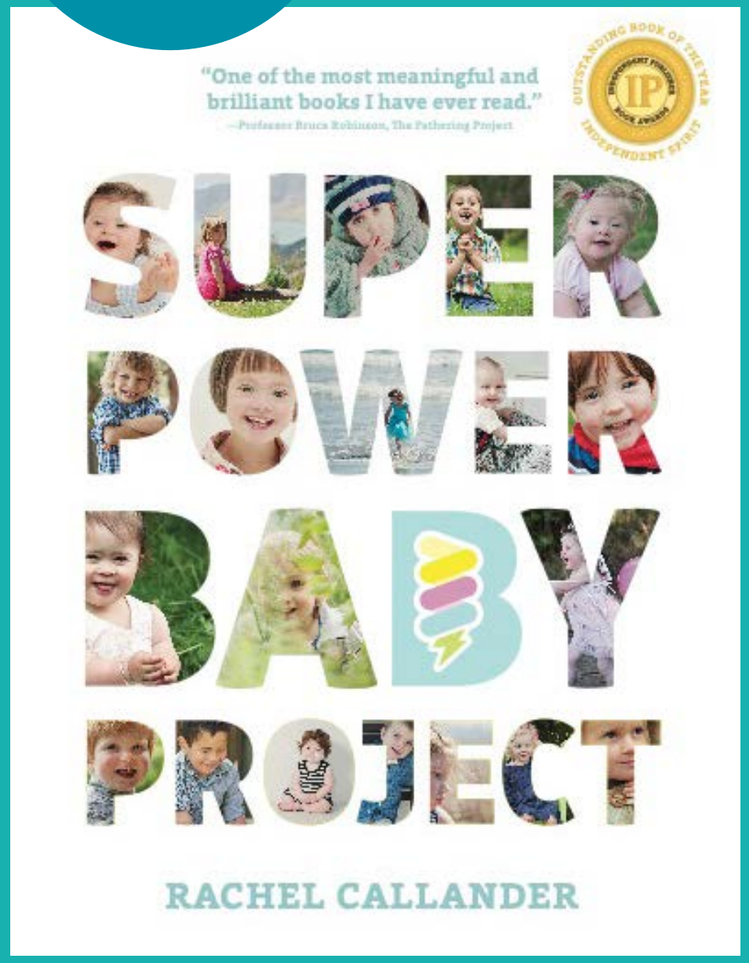
"I am still in awe of the recent talk you gave me and my colleagues at the Courage and Innovation Conference for Southern District Health Board. I truly believe you have changed my clinical practice forever."

Sarah Maley- Occupational Therapist NZ

This book belongs in every waiting room! Get it for yours.

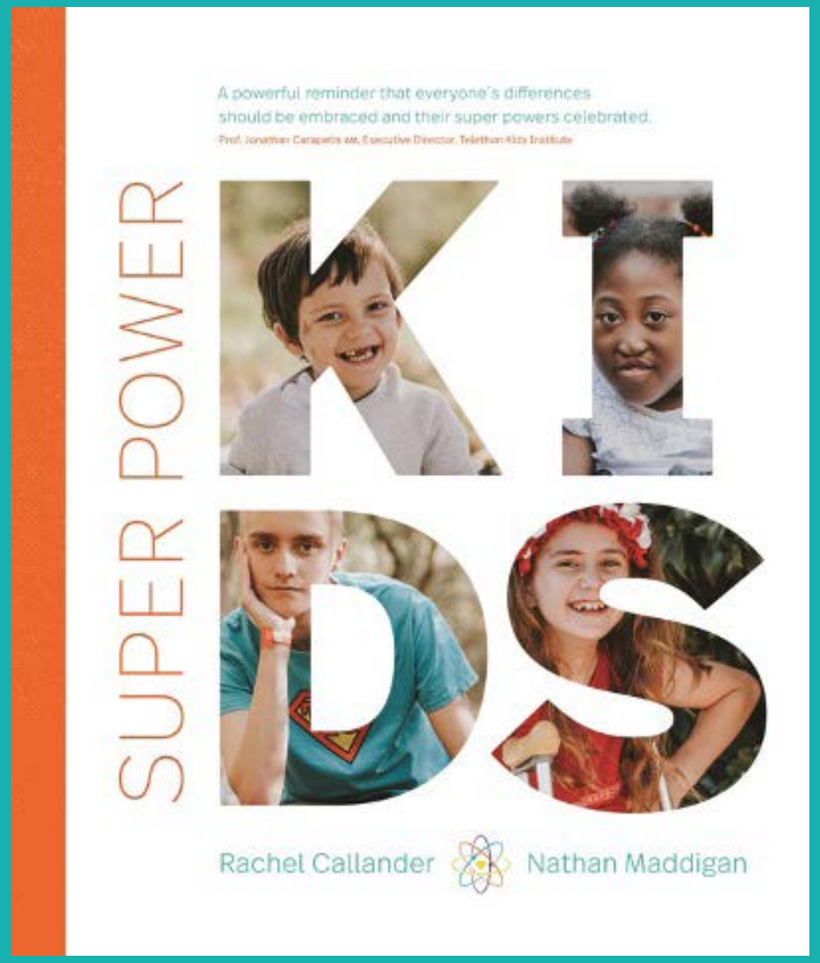
Reframing perceptions of disability

BOOKS BY RACHEL CALLANDER AND NATHAN MADDIGAN



Super Power Baby Project is an internationally celebrated book featuring striking photographic portraits of children with chromosomal and genetic conditions, taken by award-winning photographer Rachel Callander. Rachel's insights and images challenge the deficit language so often reached for when describing disability.

BUY IT HERE



Super Power Kids is the follow on initiative of the Super Power Baby Project. It raises the profile of children with disabilities, showcasing their unique talents, strengths and indomitable spirit. It directly challenges the deficit language often used around disability and instead focuses on the gifts and abilities of Super Power Kids.

BUY IT HERE

"Everyone loves your book! They find it original, moving, smart and beautiful. It works so well as counter-narrative to the medicalization of these kids.

— Josephine Johnston, Director of Research, The Hastings Center, New York.

Today I received a new referral for a child with Kabuki Syndrome. I hadn't heard of it and so googled it. So many terribly unflattering pictures and then I saw a picture that stood out above them all – it painted the child in such beauty. It was one of your pictures. From the bottom of my heart thanks for doing something that is changing the face of disability, that speaks in a language of love and compassion."

- Lynda Nicholson, Physiotherapist

RACHEL CALLANDER IS AN AWARD-WINNING SPEAKER, TRAINER, AUTHOR AND PHOTOGRAPHER.

Together with Nathan Maddigan (photographer, author, designer, trainer), Rachel delivers unique training experiences that are honest, illuminating and compelling.

She draws from a range of perspectives, that include:

1. Her motherhood to her late daughter Evie, and the years of experience as a parent in the health system.
2. Her perspective as an artist, applying right-brained emotional strength to a conversation often filled with left-brained statistics and facts.
3. The Thought Leadership Business School, where she learned to assimilate ideas and values into actionable strategies.
4. Stories gathered from hundreds of hours of interviews with families of children with rare conditions across Australia and New Zealand.
5. Relationships with health professionals and industry leaders internationally.

Rachel Callander

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