

## Fact Sheet

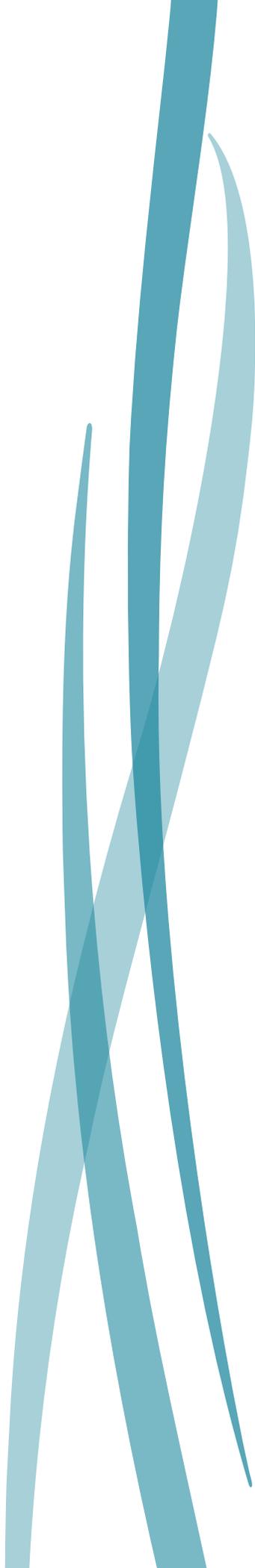
### How to Be an Assertive Member of the Treatment Team

1. **Remember that you have what the professionals lack - a total commitment to yourself, your child, your whole family**, and the responsibility of making decisions and choices in regard to every aspect of your own child's medical management.
2. **Remember what professionals bring to the case** - a general desire to help achieve the best outcomes utilizing variable amounts of specialized information and techniques more or less relevant to the needs of all people sharing a particular problem; varying degrees of mental and administrative flexibility in applying their general knowledge to a particular case; and a variable degree of personal commitment to the knowledge-base and philosophy of a discipline.
3. **You can bridge the gap!** Share with the professionals your ability to be flexible, your ability to take responsibility, and your knowledge of yourself, or your child - these are your areas of expertise.
4. **Demonstrate your knowledge and flexibility by actively participating** in the decision-making, planning and evaluation processes. Avoid aggression and conflict by assuming responsibility and taking every opportunity to be assertive.
5. **You are already knowledgeable about yourself or your child**, but, like the professionals, you should acquire a documented database. They have their "chart" or "file, and so must you. First, make your own record of the facts, including specifics (i.e. descriptions and timing of symptoms, exact details of a seizure, etc.); a diary of therapy sessions or results of interventions; and tape recordings or videos of speech or movement patterns not exhibited in the hospital, at work or in school. Second, acquire your own copies of hospital discharge summaries, specialists' consultation notes, psychologists' reports, therapists' recommendations, scans, and so on.

Make it clear from the first contact - assertively but not aggressively - with a medical professional that you expect to be provided with such information to help ensure that you understand what the experts are doing and to guarantee that you will do everything necessary to help their treatment plans work. When signing the authorization for reports to be shared among professional agencies, insert your own name in the distribution list. Ask the professionals to review what they have written with you or your child. Add your own written comments if you wish, and feed them back into the record system.

6. **You need to become knowledgeable about your own or your child's condition** and the various means of helping that are available. You need not know as much as the professionals who have had years of training, but you must be familiar with the jargon professionals use, and with the basic mechanisms involved in causing as well as maintaining disability, and the range of treatment options.

If you are not given reading material, firmly indicate that you wish to know what books, articles or pamphlets the specialist or team would recommend. **Join the relevant parent/patient organization.** Review the reading material with the professionals who recommended it, make notes of areas you find confusing, or about which you need to know more, or about which you have heard a conflicting opinion.



Use the professional as a student would a teacher - as a resource for information. But remember, you are an adult and in control of your own “curriculum”, and you are entitled to the time and individual attention you are paying for.

If you come across information that you believe your professionals do not know, try to document it then insert a copy into your “file” or write down the name of the author, speaker or other original source.

7. Remember that most conflicts stem from failure to communicate: **aggression is an expression of poor communication; assertiveness is a means of effective communication** in itself. Work out in advance what it is you wish to accomplish with the treatment team, whether it be facts, plans and objectives or feelings. Assertiveness implies initiating rather than reacting. Try to work out in advance your own areas of doubt, confusion or ignorance, and ensure that efforts are made to reduce these. It’s much harder to build on a poor foundation.

Whenever you meet with the professional team, or any individual member or professional, know your own agenda - a meeting without a clear agenda will achieve nothing.

8. **Use and take notes as much as possible.** Bring a written agenda to each meeting: “What I want to ask the doctor, therapist, etc.”, “What I want to tell,” and “What I want the meeting to achieve.”

Do not hesitate to write or refer to notes during the meeting; good professionals do it all the time. Write down answers to your questions if you are unlikely to remember them exactly, write down who is responsible for what, especially if you have been made responsible for something; and write down definitions of words if necessary.

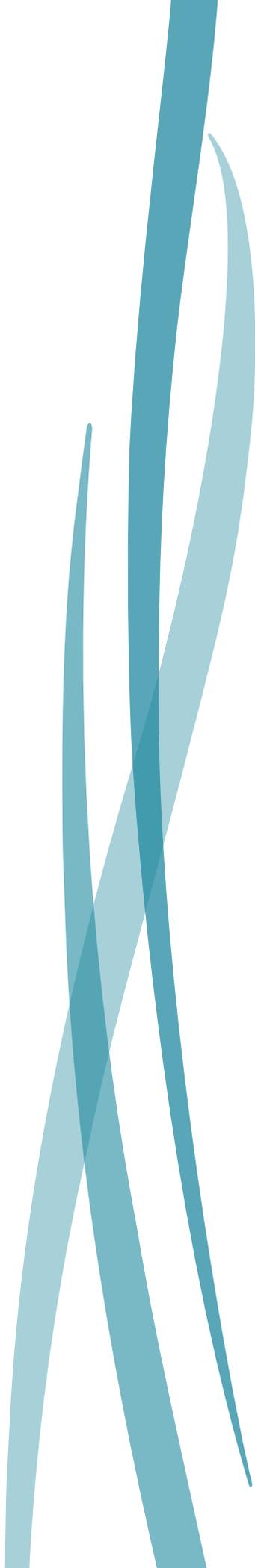
9. **Be clear in your own mind what you want professional interventions to achieve for you or your child:** ask directly if your objectives and those of the team or medical professional are the same. If not, be sure you have come to a negotiated position in regard to what is happening, why, for how long; how the intervention will be evaluated; and what will happen next if the intervention does or does not work.

**Be prepared to negotiate.** Allow for the possibility that you may be wrong and the professionals may be right - and help them accept the reverse! Remember that every intervention is an experiment: it has never been tried before on you or your child. Remember also that with the exception of surgery, no intervention (therapy, special education, drugs, treatment, diet, exercise) is likely to do any harm over a short period, so it is safe to try anything provided you set down from the start the duration and evaluation, and are objective in deciding whether the experiment has or has not worked.

**Be prepared to take the responsibility for your own experiments** - whether of commission (we’ll try it my way) or of omission (I can’t and won’t do it your way). Try to identify the obstacles to a proposed plan - yours or other team members - and suggest ways around them.

**Compromise,** you have far more flexibility than the professionals, so use this strength. Bargain - I’ll do it your way if you’ll do it mine later, or first, or in some other area. Never lose sight of the objectives, both short-term and long-term.

10. **There is no need to feel intimidated.** To achieve their objectives professionals need your help just as much as you need theirs. Within the professional relationship, you have hired their knowledge and time and it is up to you, not to them alone, to make the best use of what you are paying for. Be assertive — mutual respect is a great basis for a relationship!



**Make sure you understand the role of each member of the treatment team**, as an individual and in terms of the discipline they represent. Who is the leader? Who is the most/least experienced? What exactly does each specialist know and do? Are there disciplines relevant to the best outcomes for you or your child that are not represented on the treatment team? If so, which, why not, where are they, who knows about them? Who will advise about nutrition, exercise, career-planning, educational placement, behavior management and feelings (your child's, your own, your family's, the professionals)?

Make sure that the team knows you - your expertise; the constraints upon you in terms of your own job (time, distance, shift-work); your involvement in recreational/voluntary/political activities; your sense of how you or your child fits into the whole family system and your personal priorities and aspirations.

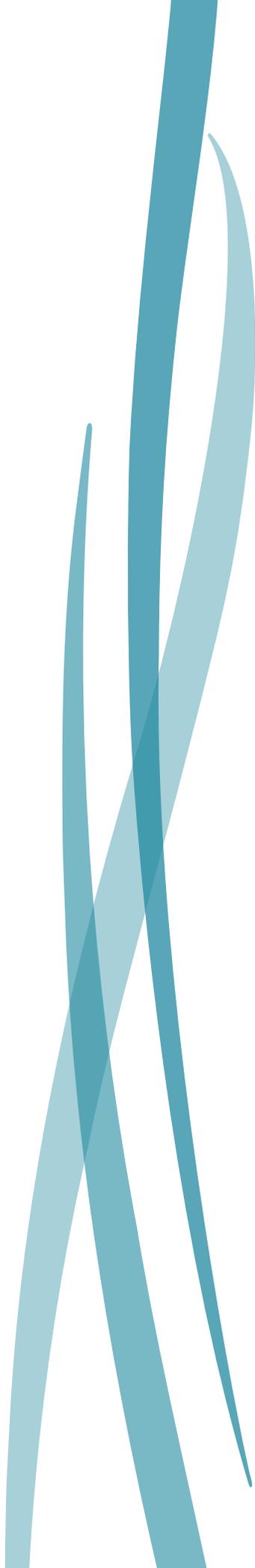
**Do not avoid talking about feelings.** If you feel intimidated, say so, and try to explain why - do you feel ignorant? (About yourself or your child, you are anything but; about the rest, it is part of the professional's job to help you be well-informed.) In the treatment situation you have the power to terminate the relationship. Does one member of the team make you feel uncomfortable? If so, you can have a say in who is present at a meeting, or explore why that individual has that effect upon you. Change the situation to diminish your intimidation and assert your own control: state the agenda, making sure the professional agenda is not ignored. Take the head of the table; limit or increase the size of the group to your own comfort level; ask a particular team member to sit next to you; do not hesitate to bring in outside support from your family, church or other helping agencies.

If you feel angry, try to say so without acting out, and try to pinpoint the source of the anger - is it relevant to the treatment, or are you still coping with earlier phases of the reaction to the condition, or with quite different parts of your life? If you feel hopeless or depressed, seek appropriate support or help and share your mood with the treatment team. How does your mood affect you, your child or your family? If you lack confidence in the treatment team, it is not fair to the professionals to hold this back. What changes would you make to give yourself confidence? Negotiate such change as is possible. Take responsibility for experiments and trials.

**If you think a second opinion would help, never hesitate to ask for one.** Often the professionals would welcome this as much as you would but have not suggested it for fear of shaking your confidence. Make it quite clear, though, what you hope to gain from the second opinion: a diagnosis, a forecast for the future, a different plan of management, or a check upon the team in whom you lack confidence. Discuss your objectives and what has prompted your request. No good professional ever objects to being asked to arrange for a second opinion. If your team refuses to discuss a request for a second opinion, your lack of confidence is probably justified and you should consider seeking alternative sources of professionals anyway. Sometimes when you explain just what you are looking for from a second opinion the existing team will be able to provide this. As always, discuss and negotiate.

Distinguish between asking for a second opinion in regard to an identified issue and what professionals call "shopping around" (making visits to a number of professionals in such a way that one visit follows another without resolution of a resolvable problem). This is a symptom of denial, insecurity, lack of either confidence or information, and is the signal for mutual reassessment.

11. The assertive individual, or parent, is not the "boss" of the treatment team, nor are they just the "client" (although use of this term reminds us who is hiring whom) but a "partner." The partner whose ultimate responsibility for the success of the whole project has the deepest roots.



**Aggressiveness will only produce defensive responses** - professionals rarely dare show aggression in return - with eventual withdrawal from the case, or passive provisions of unimaginative routine procedures rather than the personal, enthusiastic, and individualized management that displays professional skills, parental dedication and your strengths or the strengths of your child to the best advantage and outcome.

**Assertiveness yields mutual respect**, and often, friendship. Your objectives will only be achieved if you say what they are. Professionals are well-informed, hardworking and highly motivated, and respond best to similarly endowed individuals and parents as their partners.

12. **Balance your assertiveness with trust.** Trust has to grow out of experience - without taking a chance trust can never grow. As you show and express your trust in your professional partners, so will they grow in ability to trust you and accept your ability to utilize their skills to achieve the best outcome for you or your child, even if your plans are unorthodox or risky. The ability to trust in others springs from your ability to trust yourself - your own self-confidence and self-esteem as a mature adult. Know yourself and your limits, as well as your strengths and abilities. Do not hesitate to express your needs for yourself, your family, your child. If you do not look after yourself and/or your family, who will? If you do not know what is best for yourself or your child, who does?

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