

HighIQ Medical Survey



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gifted
adults
foundation



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Foreword

Dr Peter Balfour

Secretary of Mensa's Medics Special Interest Group

HighIQ Medical Survey is a qualitative report looking at the satisfaction of high IQ patients with medical consultations. Sadly, the reported experiences are mostly negative (only 24.2% were "mostly positive") and often relate to a failure of the doctor to listen or to treat their patient with common courtesy and respect. The latter is often exacerbated when the patient has attempted to help, for example by undertaking on-line research (which often seems to be like "showing a red rag to a bull"!). All too often, an important resource is missed.

It may be salutary to reflect that observations of this sort are not new in Medicine and certainly are not confined to intelligent patients. Psychoanalysts Michael and Enid Balint looked at this problem in the 1950s and a notable quotation of Michael's was "Sometimes your patients have to hit you over the head before you take any notice of them!" More recent evidence suggesting that problems still exist is the success of the #hellomynameis campaign, launched by the late (and forward-looking) Kate Granger.

It would be nice to think that this report will lead to improvement in the doctor-patient relationship but, sadly, the sort of doctors who perform badly are unlikely to read the *HighIQ Medical Survey*. Nevertheless, this is a helpful attempt to document the current situation in a selected group and, while high IQ probably makes one more prone to being irritated by "having the wool pulled over one's eyes", the findings are relevant to most, if not all, patients.

Summaries

Summary 1 – Experiences

Contrasts, The Good, The Bad, The Dangerous, The System, Do it Yourself, Listening & Discussing, Believing, Assuming, Roles, Bedside Manner, Diagnoses, Treatments

From the marvellous to the appalling, these anecdotes reflect the vast spectrum of experiences our respondents have had with medical professionals. They also highlight the various aspects of communicating and the processes of diagnosing & treating illnesses.

Summary 2 – HighIQ & Giftedness

Communicating, Understanding, Researching, Wanting Good Answers, It Helps, It Hinders, Insiders, Not Really or Hard to Tell

HighIQ people tend to want to understand what is happening, tend to do their own research and tend to ask a lot of questions. They tend to want accurate answers based on logic & investigation rather than appeals to authority. Some find that a HighIQ helps, but more find that it hinders, while a minority think it makes no discernible difference.

- **Communicating** – To a large extent, having a HighIQ makes communications more sophisticated – for better or worse – and increases the desire to participate actively.
- **Understanding** – HighIQ people tend to want to understand what is happening and have their own insights.
- **Wanting Good Answers** – HighIQ people tend to be sceptical of appeals to authority – ‘because I said so’ – and look beyond the superficial. They can often work out when they are being dismissed with inaccurate or inadequate information.
- **Researching** – HighIQ people tend to do their own research, for the pleasure of satisfying curiosity and for the safety of double-checking.
- **It Helps** – Having a HighIQ can improve rapport, spot errors, identify solutions and help others.
- **It Hinders** – Many respondents find that being questioned makes doctors uncomfortable or even hostile, particularly when they have made a mistake or when having a higher status than the patient is important to them. HighIQ people have a tendency to be sensitive, anxious or guarded and have rare or complex conditions. They can also be over-confident.
- **Insiders** – Doctors seem to respond well to those they expect to be their intellectual equals. Fellow doctors, nurses, ancillary professionals, relatives and those with good qualifications seem to fare well.
- **Not really or hard to tell** – A few respondents think it makes no discernible difference.

Summary 3 – Patients

Finding a Good Doctor, Respect, Acknowledging Limits, Establishing Rapport, Focus & Clarity, Communicating, Notes & Research, Best Practice

If you can find a compatible doctor, it's a great foundation. Trust, mutual respect and tactful communications are essential. It is important to be realistic about the situation and what is possible. Both the patient and the doctor have limited time and energy, so stay focussed on the most important aspects. Then persist until you are both clear about what is happening and what you are going to do. Prepare for consultations, make written notes and take care of your own health.

- **Finding a Good Doctor** – If you can find a compatible doctor, it's a great foundation. Trust and good communications are essential.

- **Respect** – Respect is ideally a two-way street, given and received. It is a vital part of a good working relationship.
- **Acknowledging Limits** – It is important to be realistic about the situation and what is possible. Doctors are people too and they have to work within the System.
- **Establishing Rapport** – Establishing a rapport is based on acknowledging that you are two people in a difficult situation – you are ill and the doctor is busy – but if you can help each other politely, you will both benefit.
- **Focus & Clarity** – Both the patient and the doctor have limited time and energy, so stay focussed on the most important aspects. Then persist until you are both clear about what is happening and what you are going to do.
- **Communicating** – Be tactful – you are the one who wants something and you are the one who will suffer more if you don't get it. Give reasons for your ideas, employ the power of suggestion and repeat as necessary.
- **Notes & Research** – Prepare for consultations and make written notes, both to ensure that the agenda includes everything of importance and to keep track of progress.
- **Best Practice** – Take care of your own health, including the less tangible aspects such as emotions, using all of the skills at your disposal.

Summary 4 – Doctors

Here is a summary of the advice that multiple respondents mentioned or alluded to, which corresponds with leading US medical malpractice lawyer Alice Burkin's conclusions:

Have respect and empathy – bear in mind that the patient is a human being with feelings.

Listen and observe, gather as much information as you can before coming to a conclusion. If you do not trust the patient, they are unlikely to trust you. Be clear & concise – explain how the treatment works, what to expect and under which circumstances to make a follow-up appointment.

Respect, Acknowledging Limits, Assumptions, Listening, Questions & Explanations, Medical Jargon, How the Gifted are Different, Best Practice, Other Ideas

- **Respect** is the foundation of all good relationships. Patients are people too, not just collections of symptoms.
- **Acknowledging Limits** – Both patients and doctors have limitations that must be taken into consideration if the outcome is to be successful.
- **Don't make assumptions**, particularly derogatory ones – it's unprofessional.
- **Listening** is the key skill and the foundation of a consultation. It was highlighted by the vast majority of respondents.
- **Questions & Explanations** – Asking and answering questions clearly is a vital part of the consultation and treatment process, as well as common courtesy. After all, both parties are aiming to learn something.
- **Medical Jargon** – Be aware of the difference between common knowledge and specialist jargon. Language is better used to clarify rather than confuse.
- **How the Gifted are Different** – Giftedness isn't a choice, so don't hold it against us. We seek understanding, do research, ask questions. Don't try to bully or compete with us, but rather use our gifts to help in treatment.
- **Best practice** – Understand human behaviour. Make an effort with diagnoses and paperwork. Keep up with new developments and different types of treatment.
- **Other ideas** – Appointments systems, allergy-testing & consultation agendas.

Defining Giftedness & HighIQ

The phrase “gifted & talented” is currently in vogue for describing the top end of human intellectual potential. The *Oxford English Dictionary* defines gifted as: “having exceptional talent or ability” and defines IQ as: “Intelligence Quotient – a number representing a person’s reasoning ability (measured using problem-solving tests) as compared to the statistical norm or average for their age, which is taken as 100.”

When we originally sent out the survey, we used the word ‘gifted’ as shorthand for ‘people with an unusually high IQ’ and posted it in Mensa newsletters & on various HighIQ internet forums. Mensa eligibility is specifically the top 2 percentiles, while a couple of the groups we surveyed are formed from a fraction of the top 1%. Another key aspect of HighIQ is the speed of thinking; IQ tests have a time limit. To use a computer analogy, it is processing power & speed. It is not just that a HighIQ can reason & solve problems, but that it can also do so quickly. Here, we are using ‘HighIQ’ as a single word to mean all of this and more.

Some respondents answered a supplementary open-ended question: “Why do you think you are gifted?” The range of answers showed a range of attitudes and definitions for a “tough question” that’s a “difficult one to answer”. So much so that a handful of respondents avoided committing themselves: “I don’t know”, “Not sure” and “I regard myself as extremely normal”, despite the fact that they had to be in a HighIQ group to see the survey in the first place. Another combined those ideas as: “I don’t feel gifted but was accepted into Mensa – that came as a massive surprise to me.”

Having already written plenty on the subject of medicine, it was certainly easier for respondents to write a brief yet still acceptable answer rather than embark on a whole other essay about defining ‘giftedness’. As one respondent pointed out: “I am a Mensa member. (Is that a valid answer? Sounds too easy.)” Many gave specific examples, such as: “I do astrophysics for a living, learn languages easily, play music,” “plays chess”, “for pleasure, I read graduate-level mathematics and physics texts” and “I have ‘perfect pitch’”. Many referenced the obvious objective measures of IQ tests, membership of HighIQ societies, “the exams I pass easily” and “years of acing tests”.

However, this does not mean that they think it is the only or best definition. A couple of respondents specifically questioned the whole concept: “Who is to define ‘giftedness?’” and “It’s a label affixed from the outside.” Another specified how broad even objective measures are: “With 7 billion people on the planet, even the 99.99th percentile has 700,000 members.”

The whole question invites comparisons. From the viewpoint of HighIQ people, average intelligence can seem strange and mysterious: “There are a number of people that I know that I always found miraculously lost in things as simple as everyday riddles.” Yet if lots of other people say the same thing, it must have meaning. Therefore, some people took others’ word for it: “Lot of peeps in my environment told me I was different.” “It seems to be obvious, judging by the comments I get.” Another said: “I believe I am gifted because our cat seems to consider me almost an equal.” Anyone who knows cats knows that this is high praise indeed and probably as good a measure as any. And anyone who knows HighIQ people knows that trying to get them to agree on anything is akin to herding cats, so anything they can agree on is likely to be true.

In the course of editing the responses, I realised that ‘HighIQ’ is probably a more appropriate term for the respondents than ‘gifted’, which is too broad and leading a word. A HighIQ is as much of a double-edged sword as a low or average one; it has its advantages, disadvantages & opportunity costs. As one respondent remarked: “although it may be exhilarating, it’s frequently not ‘comfortable.’” Conversely, another respondent preferred the term ‘gifted’ because “IQ as a concept did not help me find common [ground] with everyone else”.

The word ‘gifted’ has some ego-related connotations that can be seen as a negative skew, particularly in the faux-egalitarianism of modern educational ideology. The word ‘gift’ also has a positive skew in the sense that

it is a synonym for 'present', which most of us associate with being freely given something nice. As one respondent said: "I am definitely abnormal and, since I enjoy my abnormalities, I would classify myself as gifted." (Whether the abilities we are born with are given by fate, genetics, God, karma or 'other' is yet another matter.)

People join HighIQ societies because they realise that they're really not average intellectually and it is reflected in their relationships. For example: "When I have clients who are gifted, we understand each other very well. When I have clients who are not gifted, I can feel like I am beating my head against a wall to get through to them, and they get frustrated with me quite quickly sometimes as well."

HighIQ appears in every group, in both genders and every race, nationality & socio-economic class. It comes with a huge variety of temperaments, characters, other skills, interests and attitudes, but some traits are common among HighIQ people. One trait stands out as being universal among HighIQ people – curiosity. It is an interest in anything and everything, the desire to know and to understand. It is persistent study and the willingness to ask questions until one does understand. Other common traits are:

- "I have many characteristics of giftedness: creativity, complexity, curiosity, acute awareness, very high sensitivity, intensity, introversion along with intelligence."
- "I grasp most concepts easily, and make intuitive leaps of understanding."
- "Thinks 'out of the box', creative, is sceptical."
- "Generally, I find any subject I am interested in easy and pleasant to learn."
- "I think I learn differently than most other people and have an innate passion for finding out more, and using that to be better."

Methodology

Authors

In the context of this project, Rebecca Ridolfo is the author and editor, while Dr Noks Nauta is the project manager and medical consultant.

Noks Nauta is a medical doctor from the Netherlands with a degree in Work & Organizational Psychology. Her career in medicine has included a specialism in Occupational Infectious Diseases, co-ordinating education for primary care doctors and scientific research at The Netherlands Society for Occupational Medicine. She is a member of Mensa, runs a gifted adults' foundation – www.ihbv.nl – and is the author of several scientific papers & books.

Rebecca Ridolfo is a member of British Mensa. Professionally, over many years she produced publications for companies as diverse as Odyssey Travel Guides, *Human Resources Magazine* (Hong Kong), Barclays de Zoete Wedd, British Aerospace and Saatchi & Saatchi. One of her hobbies is studying medicine online.

Inspiration – Dr Noks Nauta

I heard many stories of HighIQ people who were unhappy with their consultation of medical doctors and have had my own negative experiences. This led me to wonder whether that had anything to do with HighIQ. Talking with medical colleagues, I found out that they were not very open to what I told them about my experiences. That was one of the reasons I wanted to collect more stories from gifted adults.

I presented a workshop in the Netherlands for HighIQ adults and collected experiences from that group, which were mainly focussed on communication. We (Rebecca and Noks) talked about this and saw similarities in experience from the Netherlands and the UK. We decided to collect experiences of HighIQ people all over the world, to see if we could find common themes and connections.

This study has also inspired Ms Henriëtte Pilkes, who is now performing a study in the Netherlands about experiences in medical settings. She has created a questionnaire for gifted adults and a control group. The report is ready in 2017.

Inspiration – Rebecca Ridolfo

Noks & I met through our membership of Mensa and mutual interest in health & medicine. I have suffered from a lot of chronic illness over the past decade. Consequently, I have met a lot of doctors and it has yielded mostly negative results. Naturally, I wondered what was going wrong – is it me, is it them or is medicine simply not yet advanced enough to heal what ails me? To what extent does having a high IQ affect dealing with doctors? Reviewing the book *Gifted Workers: Hitting the Target* by Noks Nauta & Sieuwke Ronner inspired me to join this project, aimed at shedding some light on the mystery by looking for common themes & experiences.

Objectives

This study is the first of its kind globally, as far as we have been able to ascertain.

Our primary goal is to facilitate communications between HighIQ adults and medical professionals. We believe this will improve both the health of all involved – all doctors are patients too, at some point or other in their lives – and the smooth-functioning of health services. While HighIQ people are – to a certain extent – unusual, much of what is highlighted applies to all people generally.

Our secondary goal is to determine whether having a HighIQ has an effect on medical consultations and, if so, what type of effect and to what extent.

Methodology

Design – Dr Nauta designed a single structured questionnaire with 4 main open-ended questions and 3 specific questions about gender, age & geographic location.

Method – The questions were sent and answers were received via email, over a 2-month timeframe.

Qualitative – We used qualitative methods (Denzin, 2009) to examine, organize, analyse and interpret the responses, with reference to Tong, Sainsbury & Craig's COREQ 32-item checklist (Tong et al, 2007). We both read the responses, selecting key points, then Ms Ridolfo edited that content, organized it into themes and summarized it. It requires little interpretation, because it speaks clearly for itself.

Conflicts of Interest – none.

Anonymity – We confirm that details have been removed or disguised, so that the persons described are not specifically identifiable.

Respondents

HighIQ: We published the survey questions in 5 Mensa newsletters and on 11 LinkedIn forums for HighIQ people – generally speaking, the top 2 percentiles.

Medical: As a self-selecting group, everybody who responded to the survey has a connection with and interest in medicine, though we did not specifically ask about reasons for responding. Most of the group have experienced chronic illness, some are medical professionals and others are their relatives. Everybody gets ill sometimes, including doctors; therefore everybody has experienced being a patient.

Prior relationship: We knew some of the participants personally beforehand and all were made aware of the reasons for and goals behind the research. Since the responses are all subjective, this could not skew the results.

Compensation: Participants received no financial or equivalent compensation beyond contributing to medical science.

Gender: 17 women & 16 men.

Geography: 13 live in the UK, 12 in the rest of Europe (of whom 4 are expats) and 8 in the USA.

Age: the youngest respondent was 28 years old and the eldest 88 years old.

By decade – 3% in their 20s, 12% 30s, 24% 40s, 24% 50s, 27% 60s, 6% 70s and 3% 80s.

The Editing Process

The first phase was to remove all identifying data and break up the text into anecdotes and memes (a phrase, sentence or paragraph expressing a particular idea). This could not be done by a computer because it is possible to say things implicitly, without using keywords. For example: "So I don't normally go away feeling that we haven't covered the ground" can be rephrased as 'I can normally give a full explanation'. "Not one who treated me worse because of my intelligence – somewhat the reverse in fact" can be rephrased as 'intelligence often helps'.

The second phase was to pick out the most pertinent, popular and clearly-phrased memes. We tried to ensure that we covered all of the ideas expressed. The third phase was the attempt to strike a balance between illustrating which memes came up frequently and avoiding too much repetition for the reader. The fourth phase was to group the responses into themes and summarize the main points. The fifth phase was to write the description of the project. We are grateful to Dr Peter Balfour for writing the Foreword, for his comments and his encouragement.

Results & Conclusions

Respondents have had a vast spectrum of experiences with medical professionals. Some subjectively find that a HighIQ helps, but more find that it hinders, while a minority think it makes no discernible difference. Taken as a group, however, clear patterns appeared in the responses and this new evidence has a number of implications for best medical practice, not only for HighIQ people but for humans generally. Broadly speaking

Mostly positive	8	24.2%
Mixed	13	39.4%
Mostly negative	12	36.4%

The advice for patients & doctors is crowd wisdom, stemming from broad experience and a great deal of thought. The fundamental themes identified by the respondents were the importance of mutual respect and good communications, of questions asked and answered well, clearly and concisely. The data contained advice about finding a good doctor, explanations of how HighIQ people are different and ideas on what constitutes best practice. Answers also covered establishing rapport, acknowledging limits, making assumptions, doing paperwork and using medical jargon.

There were three key skills that the respondents hoped for in a doctor.

1. Have respect and empathy – bear in mind that the patient is a human being with feelings.
2. Listen and observe, gather as much information as you can before coming to a conclusion and making a diagnosis.
3. Be clear & concise – explain how the treatment works, what to expect and under which circumstances to make a follow-up appointment.

Practice Implications

Humans commonly place great importance on being listened to, respected and sharing in decision-making that affects us personally. While the HighIQ adults surveyed all independently identified these core themes, I would be exceedingly surprised if anyone, once prompted, disagreed with that statement. Yet, somehow, what seems to be a combination of role-based heuristics and systemic work pressures means that these core values are all too often forgotten in the doctor-patient relationship.

Since relationships involve at least two parties, if both doctors and patients were to be more educated about what collective experience has discovered to be best practice, the overall interaction would be more successful for both parties. In other words, getting back to these basics, identifying where they appear in clinical practice and how to nurture them would create more win-win situations. The third party that would benefit would be the healthcare system itself. There are no cost-cutting measures like a quick cure efficiently delivered and like finding ways to help people cope better with chronic illness.

Future Research

This study suggests two questions that we think merit further research in the future:

1. Do disproportionate numbers of HighIQ adults suffer from rare illnesses?

We did not ask about any specific illnesses, but several were named as part of the anecdotal evidence in our survey. In a small-but-selective sample, a higher-than-expected proportion of respondents noted that they suffer from rare & unusual illnesses. Given that mind and body are a single integrated circuit that feeds information back and forward, it stands to reason that unusual thinking might give rise to unusual illness. We think it would be enlightening to discover more precise detail on incidence and type.

2. Do disproportionate numbers of HighIQ adults suffer from depression?

From a 2015 study by Dr Anne Favier-Townsend, *Perceptions of Causes and Long Term Effects of Academic Underachievement in High IQ Adults*.

"According to the Mental Health Foundation (2007), 9% of the population in the UK meet the criteria for diagnosis of clinical depression at some point in their life. This study highlighted that 43 (27.6%) of the 158 participants in the first questionnaire had mentioned that they had at some point had to be medically treated for depression."

There seems to be a high incidence of depression among people with high IQs. There were numerous unprompted and specific mentions of depression in response to this survey. Both Ms Ridolfo and Dr Nauta have noticed it in their own lives and in popular culture. For example, in one episode of the TV series *True Blood*, the Jason Stackhouse character remarks: "I never thought I was smart enough to get depressed". Another example in popular culture comes from the action-adventure TV series about a team of geniuses called *Scorpion*. The entire premise is based on the difficulty very HighIQ people have in fitting into everyday society and a recent episode included a telling statistic: 83% of people with IQs over 150 self-medicate. It is likely that further investigation would show that it is depression that is being medicated, though this could also be considered a separate subject for further research

We also believe that the question of whether the correlation indicates some kind of causal relationship merits further research.

1. Experiences

What experiences have you had with medical doctors?

Contrasts, The Good, The Bad, The Dangerous, The System, Do it Yourself,
Listening & Discussing, Believing, Assuming, Roles, Bedside Manner, Diagnoses, Treatments

From the marvellous to the appalling, these anecdotes reflect the vast spectrum of experiences our respondents have had with medical professionals. They also highlight the various aspects of communicating and the processes of diagnosing & treating illnesses.

Contrasts

- I have had mostly good experiences. However, when I communicate with my mother's medical doctor, things can be very different.
- I have met some that are great and some that are terrible. Since I have received my diagnosis, the reaction is interesting – new doctors either want to ask me a million questions because they're curious (which I appreciate, except when I'm in a hurry!) or they want me to do my circus tricks for them, to prove that I'm not a liar.
- When I have to go to specialist doctors who don't know my [medical] background, I have had to face two different reactions. The first group see my interest in what they're doing and don't hesitate to go into details. The second reaction is to identify me as a know-it-all and become condescending, because he/she is the doctor.
- In general, I would say that the majority of doctors I have dealt with (as a consumer) fall into two categories. If they are seeing you in an ER, they seem happy for any piece of information they can get, and will try to answer any question you ask ... quickly. If they are seeing you in an office, the majority seem to be threatened by anything that tries to push outside their regular pattern of operation.
- It must be morally wrong for the private ops to be conducted by the very same [NHS] surgeons in their private time; I noticed a deplorable difference in how well they treated me in consultation.
- I like lady doctors where I can show some knowledge of medicine, reason and logic and an intuitive perception of some of my treatment needs, should they arise. I find men tend to be in competition.
- "That would be very rare", they said. Yes, winning a lottery is rare too and still people do win. My treating physician stopped there in thinking, while I learned more from the internet.
- I tried to explain to several of the doctors that I can be persistent, and I know what I am asking for and why I want to see it, and that I am very qualified to understand any sort of data that the human race is currently capable of producing. One doctor, a surgeon, looked me in the eye and seemed to believe me. She recommended several good textbooks and got me a couple of reports. But I couldn't burn up her time getting all the rest of what I wanted and she was unaware of anybody in the organization who could make it happen. The radiologist was very helpful for about 2 minutes when I was able to ask him some questions about the types of machine used to produce gamma and electron beams. After that, I could get nothing useful.
- A few years back, I became aware of some medical issues arising. I did not immediately go to my doctor, because I am not in the habit of seeking medical treatment for everything. However, I did do my own research, as I always do, to see whether this particular instance would be appropriate to approach him. When I saw my doctor at the time, he was very dismissive about the symptoms I presented and said it was nothing – probably just related to the fact that I was overeating and not exercising.

I clarified that I was not overeating at all, but had in fact lost my appetite and was struggling to eat at all. I also attended a gym 3 days a week, although this was becoming difficult since I was becoming very tired and weak. The doctor totally ignored this and told me I should just “eat less and exercise more”. I asked him whether the symptoms were not indicative of a particular condition I was aware of and whether it would not be appropriate to do blood tests in this respect – or at least examine me! At this point, he became annoyed and told me he was the doctor, not me, and refused to take the matter any further.

I returned to see the doctors in the practice several times over the next two years, but they would not discuss my concerns. They reiterated over and over that all I needed to do was “eat less and exercise more”. My daughter even went with me to share her concerns that I was – in fact – usually only eating a single meal a day and, when I did eat, it was a minimal amount. Again, the doctor chose to ignore that, making the comment to my daughter that she “couldn’t see everything I snack on at work”. This annoyed me and I eventually demanded to know what his problem was. He then stated that he was tired of “know-it-all people who think they can tell me my job just because they have all those letters behind their names”.

Fortunately for me, I did move shortly after that, and the doctor within whose catchment area I fell was totally different. The first time I went to see her – which was not immediately, as I had become very wary of speaking to doctors by then! – she immediately did some blood-tests and confirmed that I did in fact have the condition that I had gone to my GP about, almost 3 years prior to that. My new doctor confirmed that a simple blood-test at that time would have prevented a lot of problems I currently have.

The Good

- I have been to some specialists who are clearly excellent. They can quickly identify what’s wrong with you, ask questions that are easy to answer and don’t complain about your answers or other responses and then succinctly explain what the problem is and how to deal with it.
- Absolutely flawless for the most part.
- My best GP was happy to work in partnership with me. I would tell her what was wrong and she’d make a suggestion and we’d try it. If it didn’t work – for whatever reason – she was fine if I stopped it. She usually had an alternative idea if her first idea caused a conflict with one of my known problems.
- I was sorry to hear that ‘defensiveness and resistance to questions seem to be the rule rather than the exception’, as this has only rarely been my experience. The last time this happened to me, it was from a hospital doctor with a misjudgement to account for. I have absolute faith in my GP and, whilst accepting that medicine is not an exact science, I know she saved my life by her rapid intervention.
- She was very good at quickly making me feel like she’d understood what I said and that she understood that what I’d been explaining about had a major negative impact on my life. She used the phrase “poor you” quite often, which made me sure that she’d understood that what I was talking about was causing me a problem.
- When my good GP didn’t know or hadn’t heard of something, she admitted it and I appreciated her honesty.
- The notable exception was one lovely lady, who listened, didn’t talk down to me & prescribed something that worked!
- We grew up attended by GPs who were family friends and later had nothing but support, good communication and friendship from our doctors. The performance levels of the doctors and consultants in Mexico and Spain were exemplary. Even across our differing native languages, communication was never remotely a problem.
- She was open to suggestions from me about what might be causing me a problem and what we might do to test the hypothesis or treat it. She was not always right, but at least I knew she was trying and I wasn’t being stopped from getting an appropriate treatment through sheer bloody-mindedness or rigid rule-following.

- I met my MD 20 years ago and he listens to me very well after he found out I am hypersensitive, fast in the brain (his words) [translated from Dutch] and very capable in telling him what's wrong or what I feel. Most of the time we do the search together to set up diagnoses. He is very helpful.
- I changed doctor to one I knew would be more open to explaining diagnosis and treatment. I feel more relaxed and have more confidence with my new doctor as he is more open to discussion and to explain alternatives to me. So when he says "I don't know", I know he genuinely doesn't.
- I have met doctors who could switch between levels very fast. That makes communication much easier, because you can say what you think and often get the right treatment.
- With my good GP, I was never in trouble for having researched my condition [implying that other doctors dislike patients researching their ailments]. In fact, she encouraged it (and sometimes told me to look things up on the Internet when I wouldn't have bothered).
- All have been very colleague friendly and listened to my problems sympathetically.

The Bad

- I find most doctors quite hard to communicate with. I am often left with the feeling that they don't really understand why what I'm explaining is a problem and that they do not take me seriously because I haven't reacted like they expected and they haven't been able to give me the support I needed to react like I actually reacted.
- I tend to find doctors frustrating. It's not usually that they are not knowledgeable, but because they tend to guess. And guess wrong. There seems to be a bias towards repeated visits trying different things, rather than taking a test and diagnosing definitively.
- Although they wanted to do good, they maltreated me more than treated me.
- I've met a few doctors who I don't know how the hell got their degree. In that case, I change to another one. I'm glad that there is a lot of information available that lets you know if your doctor knows what he/she is talking about.
- The concern of the doctor is often limited to what is needed today, not give me insight into how I will lead my life from that point forward.
- I have always thanked medical people for their assistance. I try to understand the difficulties of their jobs. I come to consultations prepared with all the relevant information. Rarely do doctors afford me the same courtesies.
- Many doctors seem to be working on the basis of outdated research. I have had bad experiences mentioning such information to physiotherapists.
- I have often already found a lot of this advice out, so they're not telling me anything new, or it conflicts with advice for one of my other ailments and they can't tell me which piece of advice to follow. I rarely bother telling doctors I have already heard their advice (or advice which has apparently superseded their advice).
- Some physicians are so keyed in to Allopathic [mainstream] medicine that they are not open to alternative medicine.
- I find most doctors will only make one suggestion of medication for a problem and the good ones make two. If neither works, they run out of ideas, shrug and start avoiding me. That is the end of their proactivity.
- I have noticed a tendency to push antidepressants on me and also to ascribe everything I have to either depression or chronic pain. I assume that's nothing to do with me being gifted, and more to do with a common modern trend towards ascribing everything for which no other cause can be found to depression, like it used to be ascribed to a virus.
- While smoking or over-eating may not be ideal, they are still better than being too depressed to get out

of bed. Making snidey comments or an outright telling-off is more likely to make patients dislike & distrust doctors, rather than magically curing their PTSD or dissolving powerful cravings. Telling someone that giving up smoking will help them live longer is not going to make quitting seem attractive to the suicidally depressed.

- Dealing with medical professionals is far worse than being ill. I avoid them unless it is something acute and obvious, like an injury or infection, which they seem to be able to cope with. Anything that does not require painkillers, physiotherapy, penicillin or prozac daunts them. They rarely make it better, sometimes make it worse and often do so in a callous or insulting manner.

The Dangerous

- My problem is in communication with occupational and insurance physicians. Although there are mental and physical problems, they deal with these totally wrong. They write in my file without any fundamental understanding. They play down the real problems and on the other hand they create problems that do not exist.
- A doctor in insurance medicine thinks he knows better and said I am fully incapable to work. He also altered and manipulated my files.
- I have had my mother's physician do the opposite of my suggestions, no matter how ridiculous it was.
- I learnt to research illness and try the standard, non-prescription solutions before going to see a doctor. One reason for that is to make sure there are no interactions with existing medications or conditions, because they usually miss that and it can be dangerous.
- My worst experience was after my eye surgeries, when the first doctor didn't know what to make of my various complaints, so he brought in a second doctor, who looked at me for 30 seconds and proceeded to tell me there was nothing wrong with me in a very condescending manner.
- My previous doctor was not interested in discussing my symptoms with me. When I asked him what his diagnosis was (after suffering excruciating back pain which had been diagnosed as kidney stones by the emergency doctor previously), he just answered "I don't know, see how you go." He would not discuss the possible causes of this pain with me.
- Later I was put on medication for high blood pressure by a specialist. It had a lot of bad side-effects, including cold hands and feet, gout, pancreatitis and kidney stones. These developed over time. My GP at the time was persuaded to change my medication. The new medication was also contra-indicated but I was still in the 'doctor knows best' kind of thinking. I was prone to gallstones and a side-effect of this medication was it narrowed your bile duct. It became painful. When I complained, I was told the medication was working.
- After a year of not being treated or helped, I got very very very angry. At that moment, they diagnosed me as being narcissistic, which caused the greatest pain I have had in my life. It was the end of my marriage too (many thanks for your help again). It has been a hell and I felt there was no place for me in society.
- I had negative side-effects and requested a medication review. A doctor I have never met nor spoken to prescribed Prozac via a 3rd party by post, writing "he feels there is no value in seeing you". If he had read my notes, he would have seen that Prozac seriously disagrees with me. So he prescribes based on feelings, rather than thought or examination, and tells depressed patients they're valueless! When I complained to the GMC, they said that "the appearance of consideration" is "adequate". I prefer reality to appearance and consider them downright dangerous. Faced with criticism, rather than problem-solving they call the patient crazy. I still have prescriptions filled to give the impression that I'm participating, to avoid upsetting these people who have zero conscience and a lot of power.

The UK System

- GP practices with a quick-pass-the-problem-before-it-stops-here philosophy.
- They never seem to be able to find a record of consultations at other hospitals.
- My 96-year-old mother gets scant attention from her GP practice.
- Most [UK doctors] seem to find patients a burdensome irritation. I believe this is more a function of the system they work in than their personalities & characters. In a target-driven system, it becomes more about getting rid of people than healing them.
- There exists a sub-culture where Hospital Trusts act (collectively) like an army, in fortress NHS, under siege conditions. Patients & relatives are treated as 'the enemy at the gate' to be dealt with & dispatched as summarily as is possible. That group ethos is the fault of higher management. I live in mortal fear of re-admittance to a hospital with such a 'war zone' ethos.
- They seem to prefer to avoid the slight possibility of a lawsuit than to alleviate my definite suffering & the potential of me damaging my eyes by scratching them, which would be 'my fault' not theirs. In the NHS, the primary aim of doctors seems not to be healing patients but avoiding litigation.
- There's no such thing any more as continuity of care.
- My surgery openly admitted that it had its system redesigned by lawyers. Their input is obvious – it is much harder to get an appointment or communicate with them generally. Rather than being better at their work, they have just raised the barriers to entry.
- Although theoretically there are alternatives to medication (that doesn't work for my condition) – such as CBT, counselling, chromotherapy etc – they are "not available" because the specialists are "very busy". Apparently, it is not unreasonable to wait ten years to see if it gets better on its own (it doesn't) before trying a different, non-medication solution.
- Don't trust the [NHS] system, as it is being withdrawn. Arrange your own treatment privately, if you can.
- The reason the NHS consumes more & more money is that it is spent on obstructive managers, complex & confusing record-keeping and treating the wrong illnesses. You can spend a million pounds treating a disease someone doesn't have, while ignoring the disease they do have, and they will still be ill a million pounds later. That is why the NHS is a bottomless money pit – most of the money is wasted. The NHS does not have insufficient staff, it has staff who use their time badly doing useless or even harmful things. Privatisation would not help – the main improvement is that paid doctors are more polite while they are being useless. The long waiting times are the result of mismanagement. Hiring more people to do the wrong things only results in more wrong.

The US System

- Telling doctors about my intellectual abilities gets me very little positive result, at great effort. My time is better spent outsmarting the administrators in the medical system.
- A number of my good friends from college are now doctors. From them, I get the feeling that the medical profession in the USA is not about healing so much as it is about profit, and the doctors are being treated as just another part of the machine. When I mention some of the experiences I have had as a medical consumer, I get doctor friends tell me things like, "they probably just don't have the resources to deal with you."
- In the USA market, I think that doctors are pretty much helpless to improve the kind of interaction they are able to have with patients, or even implement policies that allow them to react to new cases in new ways (like helping me get the information I want, from my own records, when I ask for them, which apparently never happens). They are expected to deal with me across a countertop of professional separation. That environment was not invented by the doctors; it was invented by the business administrators.

- My wife was diagnosed with breast cancer last year. I found that despite there being a great many support sites on the internet, they are mostly repeating the same material, frequently in the same words. So I started buying textbooks on oncology and radiation therapy and so forth. Soon, I was asking the doctors for access to the raw data of my wife's case, access to the images from her tissue studies, a detailed dump of the genetic data from an Oncotype DX test, details of the radiation therapy, all of it. I got blank stares from most people. They had no idea how to give me access to image data. They have no process for getting me the genetic data. They don't even have anybody to talk to when someone like me shows up asking for details.
- The insurance company does not simply accept the doctor's opinion that I cannot work, they must see objective evidence in the doctor's notes and on the forms. It was only after I became involved and provided guidance to the doctors to properly document the objective evidence that I was awarded benefits. I believe that here in the United States, this is a common problem where the insured fail to get their benefits. Most doctors do not seem to comprehend what the insurance company is looking for and do not relate objective evidence in their office notes (in my experience). Part of this is ignorance and part is the lack of time available to compose complete notes while seeing so many patients. The notes are left to the briefest amount possible to convey the visit took place and provide justification for the next step in medical care, but do little to document the actual status of the patient.

Do It Yourself

- I simply continue to take everything every doctor says with a pinch of salt and apply experimental method to their suggestions – if it works for me, I'll go with it; if it doesn't, I won't.
- I had to learn about this stuff to be proactive about my health needs; they seem fine with that. Learned to figure out what was going on and then check with the doctors.
- My present GP wanted me to take steroids to reduce my cholesterol levels. I refused and said I would prefer diet. I knew porage, beetroot and onions could reduce cholesterol. The doctor was doubtful, but did not try very hard to dissuade me. It appears to have worked.
- When my daughter was about 6 months old, we took her to the paediatrician because of a fever. She was diagnosed with an ear infection, given antibiotics and sent home. About 6 weeks later, the same thing happened. This time, the paediatrician announced that he was going to schedule her for surgery, she needed tubes in her ears. I don't believe in modifying or removing body parts unless it is absolutely necessary. For about a half an hour, we discussed the pros and cons of tubes and his rationale in deciding the tubes were needed.

The doctor was so frustrated with me questioning him, that he finally announced he was out of time and that I needed to trust him if we were going to have a good relationship going forward. When I asked him if he was absolutely positive he had completely eliminated the first ear infection and this one we were dealing with was not a regrowth of the original infection, but a brand new one, he got very quiet and told me he was not sure. I asked him: "Why would you subject this child to surgery before you have used up all your other alternatives?" The next antibiotics he prescribed cleared up the infection and after that my child never had another ear infection.

- The second event happened about 2.5 years ago between my wife and her gynaecologist. I would like to preface this story by saying this doctor (male, 65 years old) was one of the most caring physicians we have ever met. When my wife started going through menopause, she started bleeding heavily due to fibroid tumors. We tried the hot water bag inserted in the uterus and the RF treatment to shrink the tumors, but neither worked and the bleeding continued. My wife finally passed out one night at a restaurant due to excessive bleeding. She had lost almost 50% of her blood. Her body just couldn't make it fast enough.

After she got out of the hospital, her doctor told her she needed a hysterectomy. My wife did not want this, because she knew too many women who had prolapsed and needed additional surgeries. I started doing my own research and went with my wife to her next appointment. My research showed the tu-

mors were active during the menstrual cycle, so I suggested to the doctor that we put my wife on the Depo birth control shot. There were no negative side-effects and it could be stopped anytime to see if she had completed menopause. He looked at me dumbfounded, but to his credit he did say that no one ever thought of this before and there is no reason it shouldn't work and no harm if it didn't. After a year and a half on the shot, she is fine and still has all of her parts.

- I was diagnosed with chronic fatigue syndrome in 1993 and fibromyalgia in 1999. I have an eight-year gap in my work history, due to the combination of these conditions. BUT I am no longer disabled and have regained a large measure of health and ability to work and function. I have been working full time (and then some) again since November 2007. I have regained my health largely through working with both allopathic physicians and alternative health practitioners (Chinese medicine, acupuncture, herbalist and massage therapy) and drastically changing my lifestyle, eating habits, etc. Some MDs don't want to hear any of this; others are open to it. I have learned to talk about it only if/when necessary and to be very careful how I describe what I have done and why. In one conversation recently, with my primary care doctor after he diagnosed me as pre-diabetic, I said to him: "I'm very aware that you disagree with what I've done. I know that there are no double-blind studies that prove this. All I know is that the vast majority of people who have had the same diagnoses as I have had are disabled for the rest of their lives and on many medications, including narcotics for pain control, while I have regained my health enough to work full time and be on very few medications and no pain meds. I believe in using the best of both allopathic and alternative medicine, and that's what I will continue to do." At my most recent appointment with him, I had lost 20 pounds in four months by changing my diet. I have a BMI of 22, coming down from 24. This lifestyle change and resulting weight loss got his attention and his respect. My blood work is pending; if my cholesterol and blood sugar numbers are better also, I think that will gain his respect even more.

Listening & Discussing

- When a decision had to be made between a triple bypass or stents, each of the 3 or 4 consultants involved came and sat down with me to discuss the pros and cons at some length and ended by doing what I finally decided was the better choice. To my astonishment, consultants in 3 hospitals have suddenly thrown out compliments like: "I think you're great" and "We're all full of admiration", which did wonders for my morale!
- Mostly they are happy to explain and discuss.
- This all arose from an episode when I was 31-35 that almost killed me. Learned to figure out what was going on and then check with docs. I always explain that experience to them, so that they understand why I need to be briefed technically. I guess I've been lucky – mostly they are happy to explain and discuss.
- My experience is that when I want more and specific information, I have received it from most members of the medical profession.
- Once I had a meeting with a psychiatrist and, at first, he was trying to give me a description of something that did not exist. At the moment I told him it was bullshit, he turned and really listened.
- My good GP did not have a problem with me knowing the medical names of various body parts and nor did she try and force medical names of all body parts on me.
- Many doctors do not listen well.
- In 12 years, I have changed general practitioner three times, because I had the impression they were not listening to me. The one I have now is still not listening, but I am now too tired to look for a good doctor.
- If a doctor is hesitant to give more information, I start feeling a lack of trust.
- Doctors do not take the time to provide the depth of information I desire and become impatient when I ask questions.

- Many times I have found that the doctor will become uncomfortable when I ask them questions, as if they would prefer me to just blindly accept what they say without question. Also, when I have spoken to them and challenged them when they have said that there is nothing amiss, they become annoyed at this and defensive.

Believing

- I generally got the impression she believed me when I said I thought X had caused Y and that she was happy to work on that premise until/unless information to the contrary came along.
- I now quite often go through the motions as I wait for the doctor to experimentally prove that what I've just told him or her is true.
- I told my then GP that I was depressed because of my mother. He refused to believe that this was the cause and sent me for counselling to find out what the real cause was.
- I asked to see another doctor in the practice, which I did, but she was immediately defensive when I started speaking to her. When I finished explaining my concerns, she stated that my doctor had spoken to her and told her there was nothing wrong with me. I asked her if she was going to examine me. She stated that it wasn't necessary – she trusted her colleague.
- Every consultation with him felt like a battle to present information in a way he could accept and would believe. I learned from him not to present my conclusions, but where possible to present my evidence and allow doctors to draw their own conclusions. This means I now often leave information out.
- Having a geneticist in their own organization diagnose me doesn't seem to carry a ton of weight.
- During a visit to a throat specialist, she was pushing hard on my neck and, at my reaction, she said: "It cannot be that painful!" I think I am the one who knows how painful something is.

Assuming

- But the general pattern is that I seem to be assumed to be less intelligent than the average doctor, by doctors.
- I go to specialists I have no interest in seeing to provide my latest GP with reassurance. Last time I did this, I had no interest in communicating anything to said specialist. I didn't believe they could add anything to what the last one had said, whereas my GP believed knowledge would have moved on in the last 5 years – I was the one who was right. The letter that came back from [this specialist] contained a large number of inaccuracies.
- I was put onto another pension ('Bijstand') without any possibility to get work. Although I belong to the 2% most intelligent people (IQ in official WAIS above 130) and have a strong working memory, I am treated as if I could not give any contribution to society.
- Shortly after a female head poked through the door and looked at me and then down at the ashtray on my bedside locker. I was told: "You smoke too much. Good morning." She had never even asked me if it was I who smoked. Later, the Charge Nurse came back and said: "Tomorrow, you go". The next day, I got dressed and went to his office. I asked: "Could I have my legs redressed before I go?" I showed him my legs [injured in a car crash]. I couldn't resist saying I did not get this smoking.
- They diagnosed me with an autistic disorder. I see that as an extra, but most people see it as a handicap.

Roles

- Some physicians need to be the one with all of the good ideas, so that they cannot tolerate good questions or good ideas from their patients or patient's families.

- Part of the problem is the attitude of medical doctors like: 'we know what is the case'. For them, it is a problem to have a patient who is not medically educated, but can change levels very fast.
- It seemed like asking questions was in a way not trusting what they said or lowering their status. I think those doctors can't accept being challenged by someone other than a doctor.
- I go to specialists I have no interest in seeing to provide my latest GP with reassurance.
- When working with a neurologist to manage my migraine headaches, about 15 years ago, I studied the area enough to know that it would be very useful to have a simple computer program that tracked various potential migraine triggers. I offered to build such a tool and give the data to the doctor, and asked him if he would be interested in using it. He looked at me like I was a moron. So I mentioned that I actually had some scientific background (studied engineering and physics at Stanford, worked in a bio lab at NASA for two years), plus 15 years of experience developing software applications, plus a strong natural gift for analysis. He seemed even more offended by my effrontery.

Bedside Manner

- I have known 2 doctors with such charisma that just consulting them makes patients visibly feel better. I think it may have something to do with energy, because I caught the moment – with one of the two – as he came through the door and called up those reserves of energy. That same doctor treated everyone around as an important human being.
- The consultations flow smoothly and we make it a pleasant moment by surprising each other with a comical representation of the problem and the possible solutions.
- Both of us have long been good communicators and maybe our use of humour has played a part in the cordial nature of our 'medical experiences'.
- Top man in performance and a very funny guy too – a real pleasure to meet.
- Both of them greet me as if they are pleased to see me, talk to me on the assumption that we are two intelligent people communicating, answer any questions, share jokes. They took enormous trouble at the London Chest Hospital to discuss it all with me.
- We have always made jokes with our doctors. We have always thanked our medical people at all levels for their assistance. We have tried to understand the difficulties that their jobs make for them. We have never seen any doctor as our superior – in fact, neither of us has ever viewed anybody as our superior – while we try to balance that by not viewing anybody as inferior. Simply, some people are good at one thing and some at another.
- It has been my experience that if you use a correct medical name, some doctors seem to embark on a mission to use all the names of all the parts of the body until they catch you out on something you don't know.
- When working with another neurologist, who found a much more effective treatment for my headaches, I mentioned in one of their office's regular OTC questionnaires that I had started taking melatonin occasionally, for its anxiolytic effect. The doctor began lecturing me vehemently on the dangers of taking non-prescription supplements. I tried to point out that I had done a good deal of research on the topic, purchased from a reputable source and manufacturer, and tested my body's reaction with small doses just to be safe. Hey, we're talking about melatonin here! When I mentioned that I was actually pretty qualified to make a decision about taking melatonin, the doctor became visibly angry. So I apologized, left and found another doctor. I did not get to the part of my argument where I pointed out that the supplements I was taking were being sold over the counter in the pharmacy in the same building as the doctor's office.
- He has the very frustrating habit of answering the phone, even when a patient is sitting in front of him. This annoys me a lot, as I find it rude and showing lack of concern.

- My worst experience was in Italy, with a psychiatrist I went to see during a period of great distress. I told him that among the many reasons I was feeling down, I did not feel comfortable living in my home town, which I never liked. He reacted as if I was crazy. He actually said something like: "I cannot believe you don't like living here, this is such a great place". I was appalled by his reaction and found it completely unprofessional and paternalistic. He was not supposed to judge me, but to help me. Obviously, I did not go back after the first visit.

Diagnoses

- At an after-school consultation about a 'bad' left shoulder:
 Dr – "What's in the bag?" (which was at my feet).
 Me – "My marking for this evening."
 Dr – "And do you carry that regularly?"
 Me – "Well, yes, most days." (I began to see the drift of this conversation.)
 Dr – "Which shoulder do you carry it on?"
 Me – "The left – I don't really need you, do I?"
 Dr – "No – we both know what the problem is."
 Me – "Stop carrying the bag."
 Dr – "Well, find another way – obviously you have to do your job".
- I have had burn-out and other mental health issues in my life that have evaded consistent diagnosis, beyond obvious morbidity.
- I would simply report the findings from the latest specialist when asked what was wrong with me, rather than saying things like: "The first specialist diagnosed me with food allergies, but the second one did a different test – which he said was superior to the first – and concluded that I don't actually have allergies, I just have reactions to certain substances, such as vomiting or my lips swelling up to twice their size for reasons that medical science cannot yet name. But then again, every medical professional I talk to seems to have a different view of what the word 'allergy' refers to anyhow".
- I've been mis-diagnosed in a couple of instances.
- I kept records of my symptoms, in a chart that could be viewed at a glance, thinking the doctor would find it useful. She found it annoying. She did not want to find out any detail beyond knowing the broadest category of disorder. I cannot begin to guess how she justified rejecting this information, as I doubt she would admit to herself that she prefers guesswork to observation or questioning, even when I make it easy for her.
- At times, I find it frustrating talking to him because he's focussing on symptoms and missing the whole picture. Sometimes I suggest to him I should take some additional test to check something "peripheral" and he agrees with me.
- My experience with specialists is that if your GP doesn't already know what's wrong with you, they can't find out (and will be rude to you into the bargain; whereas if you've gone private, they'll restrain themselves to superior and patronising).
- When I was 12, after the ophthalmologist told my mother that I had to get glasses because I had myopia, I told him that I had astigmatism. He checked it and I was right. I was a little bothered, because I thought it was very unprofessional that he didn't notice something as simple and a little girl had to tell him how to do his work.
- I was 7 months pregnant and I visited a doctor to check my blood analysis, because I have some abnormal values. He said: "This is related to severe alcoholism". My husband and I felt like calling the police, but we decided to visit another doctor instead.
- I spent quite some time explaining to one doctor how I was suffering from a significant loss of appetite and resulting weight-loss. However, I was wearing several jumpers, because another consequence of

that was really feeling the cold, so I didn't look skinny at first glance. Apparently, he thought a glance was better than a physical examination and actually listening to me. I later saw in a report that he thought I had no problems with food, which may explain why he prescribed such a powerful medication. Luckily, I was suspicious of him and only took a third of a tablet, because that was enough to knock me out for 36 hours and make me feel exceedingly ill for a further 24 hours. I believe that if, in my weakened state, I had taken a whole tablet, it would have killed me. Listening is important.

Treatments

- Type-2 diabetes: Again, I refused medication and said I would prefer to try diet first, as my diet had plenty of room for change. My choice was respected.
- If medication isn't suitable or doesn't work, they will tell me the standard solution – eat more veg, join a club, apply the principles of sleep hygiene ... I tell them I've already tried it & it didn't work. They repeat the standard information and continue to do so, regardless of what I say. I have come to the conclusion that the minimum is all they've got, but they don't want to admit it.
- When my immune system disorder was not yet assessed – and I still had infections and a hopeless discussion with my lung specialist, who was sub-specialized in immune disorders – I used the combination (feeling, facts and knowledge) to get a treatment with immunoglobulins.
"Your IgG levels are now OK."
"That is fine, but last time it was not the case and I still don't feel well. I am tired, I have a fever, headache, pain in my ears and I am short of breath."
"Your lung function is OK."
"Yes, but my normal score is 130% of the norm and at the moment it is not. And as I said, I do not feel well. Also it was assessed that I do not produce enough antibodies against certain bacteria. The prescribed dosage of antibiotics does not work anymore, because I had two infections."
"This should work out differently."
"Maybe, but not with me, because I still don't feel well and have two obvious infections."
Then, finally, I received – maybe they wanted to get rid of me – immunoglobulin. And I improved substantially.
- In the UK, doctors do not keep proper records. If they don't read the notes (assuming they exist at all & are accurate), each doctor has to start again from the beginning and if you never see the same one twice, collectively they never get further than the beginning. For example, I have had the same eye allergy for 35 years. Every time I go to the eye hospital, they cannot find my records and try to give me antibiotics, which do not work because it's an allergy. Instead of a single visit, I have to go back 3 or 4 times while they reinvent the wheel, ignoring what I say about what has worked in the past. Each time, another useless prescription. If they finally work out that what I told them during the first visit was accurate, they are surprised. If you extrapolate that across the entire health service, costs are tripled or quadrupled.
- When I explained to another doctor that I felt pain in the adductor when running, he told me: "In that case, do not run". And he wasn't joking! I felt like kicking him, but instead I decided to visit another doctor.
- The hospital wanted to do an operation on my toenail. They flatly refused to give me any information about taking care of my feet. I went to a private chiropodist, paid £30, he fixed my toenail without surgery and gave me good advice. I have had no problems since. The NHS wanted to spend far more money making me sicker; not just once in recovering from an unnecessary operation, but thereafter by ignoring the preventative aspect.

2. The Effects of Giftedness

How do you think giftedness has affected your experiences?

Communicating, Understanding, Wanting Good Answers, Researching,
It Helps, It Hinders, Insiders, Hard to Tell, Not Really

Gifted people tend to want to understand what is happening, do their own research and ask a lot of questions. They tend to want accurate answers based on logic & investigation rather than appeals to authority. Some find that giftedness helps, but more find that it hinders, while a minority think it makes no discernible difference.

Communicating

To a large extent, being gifted makes communications more sophisticated – for better or worse – and increases the desire to participate actively.

- I thought I just explained what was wrong with me and – based on what I felt and what I knew about my disease – I came to a conclusion.
- I expect to be a part of the decision-making process and not to be told what to do without understanding the whys and wherefores of things.
- I verbalise some understanding of medicine and the thought processes in decision-making. I make my intellect and sensitivity abundantly clear to the doctor, as I will not be spoken down to if possible.
- The questions I ask come from a high level of sophistication.
- I have never had a problem communicating.
- I have been and am a well-greased communicator and I most certainly can express myself, get my point across, address sensitive subjects or go into areas maybe the doctor wants to avoid (such as cost, side effects, other options, et cetera).
- By and large, when I speak, they listen. The by-&-large factor manifests itself in that I am not always allowed to complete my detailed exposition of symptoms, with such history thereof as, to my mind, could have a relevance to the professional interpreter – how am I to know? – such that he/she needs at least to hear it in its fullness. I then find occasion, later on in the dialogue, to come back to whatever has been missed out.
- If I weren't gifted, I suspect that I wouldn't be able to ask questions like "can you actually do anything for me or are you literally just going to monitor my condition?"
- I have learned to be very careful how I describe what I have done and why.
- My knowledge of medical terminology and medical concepts helps me communicate better.
- Possibly I have the linguistic skills necessary to use the correct medical terminology.
- I have learnt to avoid using medical names for body parts with doctors I don't know.
- It increases my anxiety and frustration when my questions are not answered.
- I found that when people do not take me seriously, I become angry. I argue more.
- If I weren't gifted, I assume I largely would speak like I think a 12-year-old speaks and not know the proper names for things, not be able to draw valid conclusions on anything even slightly complicated and not be able to control my visible and audible reaction to stimuli. I would simply report the findings from the latest specialist when asked what was wrong with me. I started "crying out in pain" when specialists examined me in a way that caused any level of pain. I have in the past been in

extreme pain and did not make any sounds as a consequence. I no longer rely on doctors to realise that level of pain does not correspond well to noise made and I therefore now try and make the noises they are expecting. It helps to imagine what your 12-year-old self would have reacted to and how.

Understanding

Gifted people tend to want to understand what is happening and have their own insights.

- I know way more medicine than the average patient.
- She has quite openly said that she values my insights because I am logical with my observations.
- I combine my giftedness with knowledge, expertise and intuition.
- I am aware of the additional information needed.
- I can usually understand what they tell me without much explanation.
- I have found that I must do my own research and carry everything doctors tell me out to the next level by myself, because in almost every case, the doctor is either unwilling or unable to provide sufficient detail on the process, to help me understand what is happening to me.
- I like to know a lot of details, as I feel that I understand something properly when I know more than the obvious information.
- So I often knew something was wrong without evidence. Sometimes proof was found several years later.

Wanting Good Answers

Gifted people tend to be skeptical of appeals to authority – ‘because I said so’ – and look beyond the superficial. They can often work out when they are being dismissed with inaccurate or inadequate information.

- Intelligent people are more likely to question what the doctor says.
- [Being gifted] probably helped to save my life when I was 35. Keeps me from unquestioningly accepting a diagnosis when the symptoms don't actually appear to match the diagnosis well.
- I might ask more questions than others. I wouldn't accept a treatment that doesn't seem to be correct.
- I have always queried things that most people take for granted or accept at face value when they get told.
- I think doctors generally don't expect someone to ask as many questions as I do and to expect clear, logical answers. I will not do something just because a doctor tells me to, I need more information.
- I think that it makes me inclined to ask more questions and not be fobbed off when doctors are evasive. Some doctors in the UK may find questions difficult to cope with because they have a limited time to give each patient.
- I do acknowledge that it may be challenging for a medical professional to deal with a gifted individual, since we do tend to ask a lot of detailed questions and do not accept “because I say so” or “just because” answers.
- I generally find that when talking to a medical professional, I ask a lot of questions that are mostly not answered in a satisfactory way. I always feel that they do not talk to me as an intelligent being, but as someone that could not possibly understand what they do in their job.
- [If I weren't gifted], I assume I'd be less sceptical and more inclined to believe what doctors say without following the logic through to the bitter end. Perhaps I wouldn't realise that the advice they'd given me for problem A conflicts with the advice for problem B until I tried the advice and it caused problem C, rather than the moment they said it.
- I guess I can somewhat feel the answers that are not accurate, when the doctor is trying to give an answer he doesn't really know.

- I find it hard to take advice from doctors seriously. Much of it is advice that is generally available.
- I don't trust doctors who can't explain their reasoning.
- I've learnt to mistrust an MD's advice and rely on my own knowledge in many cases.

Researching

Gifted people tend to do their own research, for the pleasure of satisfying curiosity and for the safety of double-checking.

- I believe most of the 'gifted people' I know have a considerable curiosity.
- Intelligent people are more likely to go into the surgery having looked up their condition.
- We also tend to do our own research, so that we know what we are talking about when we speak to specialists.
- Even if I did not study medicine, I always try to find out about illnesses and medicines' components. I hardly ever take pills without having checked what is in it, which percentage and what the effects are.
- Since we have the Internet, we know much better than before how they come to conclusions and so we can give comments.
- When my doctors explain why they suggest a certain intervention, often that is something I already know.
- [If I weren't gifted], perhaps I wouldn't listen to medical podcasts and probably I wouldn't remember the information contained in them and I wouldn't know it conflicted with what my doctor was saying. Perhaps also I wouldn't second guess them and suspect them of trying to treat me primarily with the placebo effect.

It Helps

Giftedness can improve rapport, spot errors, identify solutions and help others too.

- I have found that, at times, being intelligent and asking intelligent questions can get me (or my family members) better medical care. I have gained the respect of physicians.
- Makes for entertaining interactions with the medical people – many of them enjoy someone who is at least familiar enough with their work to appreciate that they do it well.
- Not one who treated me worse because of my intelligence – somewhat the reverse in fact.
- I am not intimidated by their amount of education and/or knowledge.
- My primary doctor generally sends me to specialists whenever I want now, because she knows that I know more than she does about my condition at this point.
- I have found errors in Hx and Px records 3 times while sitting in an emergency room waiting for a family member to be treated. When I report those things to ER staff, I make sure they are paying attention, because it is an ERROR I have found. So I am pushy, but apologetic, and do not mention my ability to comprehend new material, remember old material and so forth. The response in these cases has been good.
- I think that if you have more knowledge, it allows you to detect a bad professional. That is good, because you can change to another one.
- Thanks to what I was taught by my mother [a nurse], I can avoid bad prescriptions from bad doctors.
- Satisfaction that they acknowledged that you were right and you got the right treatment. Your life becomes much more agreeable.
- Satisfaction that you added something. Five years later, the Asthma Center went to the young adult

group of the Asthma Fund because their program did not fit their young patients. Afterwards, I was told that I had added to that. It gives me a good feeling that I was not mad and have done some positive thing for others.

It Hinders

Many respondents find that being questioned makes doctors uncomfortable or even hostile, particularly when they have made a mistake or when having a higher status than the patient is important to them. Gifted people have a tendency to be sensitive, anxious or guarded and have rare or complex conditions. They can also be over-confident.

- Doctors find it awkward when you show them the weak points in their arguments.
- I have a medical issue which crops up occasionally, where I find GPs are generally ignorant; I know a lot more about the condition and its treatment than the vast majority of GPs. And this can be a problem for getting treatment from them.
- I have seen patients in hospitals where I have worked who I believe are likely gifted, who needed to know more than most people did, and who had good ideas about their treatment. Those good ideas were dismissed with “they want to be in charge of their own care”.
- My MD doesn’t like to see me anymore, because he is becoming insecure when trying to help me, because I question his diagnoses all the time.
- Sometimes I think I seem more aggressive and arrogant than the average patient.
- He then stated that he was tired of “know-it-all people who think they can tell me my job”.
- The fact that I am actually extremely smart, if I point it out, never seems to improve things and sometimes makes doctors more upset.
- To describe myself as ‘gifted’ to someone like a medical professional, and expect to be treated differently because of it, sounds like a sure-fire method of getting their backs up.
- I think part of doctors’ dismissiveness stems from the idea that if you’re intelligent, you should be able to cope on your own or be smart enough to work it all out for yourself. They seem to miss the fact that high intelligence can cause its own social & emotional problems, as well as being little help in conditions such as insomnia or allergies or chronic pain. Doctors seem to think that, somehow, intellect is the solution to all problems and you are selfishly wasting their time, when they could be helping someone less able to fend for themselves.
- I know I sometimes bother doctors with my questions.
- Gifted people have communication and hypersensitivity issues and may face stigmatisation from the non-gifted.
- Understand that these gifted characteristics can feed and heighten anxiety.
- I’ve noticed a lot of gifted adults tend to over-work and are reluctant to admit or show weakness.
- Partly it is because my illnesses showed in an unusual way or were quite rare. My lung function is about 130%. When I do not have enough breath, I still have a lung function of 100%.
- I also find that highly intelligent people who have a high opinion of their ability to be right all the time are still sometimes wrong, and when they are wrong, the impact is much worse than a moderately intelligent person who double checks everything and questions himself.

Insiders

Doctors seem to respond well to those they expect to be their intellectual equals. Fellow doctors, nurses, ancillary professionals, relatives and those with good qualifications seem to fare well.

- My mother's father was a physician also, so I am not intimidated by physicians like many people are. I also have a Master's Degree in Social Work and am licensed as a psychotherapist as well. I have had mostly good experiences.
- Absolutely flawless for the most part. ... I am an investigator in forensic pathology & clinical forensic medicine.
- My GP is very good. He is gifted himself, takes time to hear my opinions. He thinks together with me and likes to explain what he knows.
- For many years, neither of us ever saw a doctor who was not a member of our family. We grew up attended by GPs who were family friends and later had nothing but support, good communication and friendship from our doctors.
- I didn't really have issues with my doctors, as they knew my mother is a nurse and now I even have a mother-in-law who is a doctor. They understood that I have a kind of medical knowledge and didn't complain about my questions.
- I make my profession known [Medical Technologist], so the doctor will talk to me instead of just dictating instructions. My intelligence shows. This works, but also leads to the doctor assuming I know more than I do. They throw out more obscure jargon than usual. Whether this is the assumption I speak their lingo, or the typical smart-person one-upmanship, I don't know.
- The doctor was known to be very kind to children but was very fierce with adults who she thought were just looking for a couple of days off work. Before I spoke she demanded to know what was the matter with me. I responded: "Well, nothing, I hope. I just need a certificate to say so before I can start as a nurse." She was a changed person. At the time, certificates cost a shilling. I wasn't charged.
- With one slight exception, I have been asked early in the conversation what my job was (lecturer in English) and then treated in a friendly, relaxed and courteous manner as an intellectual equal.
- Another problem with my doctor was when I suffered from depression. Whenever I went, the doctor didn't take me seriously because I wasn't in tears. When I went with another episode, but after taking a degree in psychology, he simply said that I must know what I was talking about and referred me for treatment.
- The British middle-class all seem to hold this innate and unshakeable belief that anyone who was really intelligent would be just like them in terms of social status and income. If you're not, they look down on you.

Hard to Tell

- It's actually quite hard to recognise other gifted people unless they have some really obvious signs that they are gifted. Mensa meetings suggest that most gifted people show no obvious signs of being gifted.
- It's hard to be sure. How do you ask someone who's avoiding you why they're doing it, when they won't speak to you? Even if you do ask, they may or may not be willing to tell the truth. Also, they won't necessarily be aware of the reason, as it may be rooted in deep-seated unconscious attitudes.

Not Really

- I do not think it has.
- Anyone can have problems with their doctor.
- It has more to do with being determined, informed and articulate.

3. Advice for Patients

What is your advice for gifted adults?

Finding a Good Doctor, Respect, Acknowledging Limits, Establishing Rapport, Focus & Clarity, Communicating, Notes & Research, Best Practice

Synthesis

Here is a summary of the advice that multiple respondents mentioned and alluded to:

If you can find a compatible doctor, it's a great foundation. Trust, mutual respect and tactful communications are essential. It is important to be realistic about the situation and what is possible. Both the patient and the doctor have limited time and energy, so stay focussed on the most important aspects. Then persist until you are both clear about what is happening and what you are going to do. Prepare for consultations, make written notes and take care of your own health.

Finding a Good Doctor

If you can find a compatible doctor, it's a great foundation. Trust and good communications are essential.

- Do research before choosing an MD – get one with a good 'bedside manner' and communication skills, in addition to good medical knowledge and skills. Ask around for this. Ask nurses who they would take their family members to. Look at online review websites. Check them out as much as possible before choosing an MD.
- Try and find a doctor who's happy to work in partnership with you and actually listens (forego one with more apparent medical knowledge for these skills).
- People who know their stuff don't mind explaining, if you are really listening and especially if you ask good questions. And if they do resent being asked for deeper explanations, that's a red flag – maybe look for another healthcare provider.
- If you do not trust your doctor, get another one.
- Always get a second opinion if you think the first doctor you consulted is not really listening, you don't trust him/her or you are really worried.
- Look for a doctor with whom it does work. It is so pleasant to have doctors who do what has to be done.
- Look for gifted doctors.
- If your doctor tells you that you can be cheerful despite being ill, you know you've found a good one.
- Keep a healthy sense of scepticism about psychology and psychologists.

Respect

Respect is ideally a two-way street, given and received. It is a vital part of a good working relationship.

- Bottom line, insist on shared decision-making.
- They should listen to what their doctor has to say, but be prepared to put their own case and not allow themselves to be dismissed lightly.
- Do not accept it if he or she disregards your proposals about what may be the problem.
- Respect the doctor's education and experience, even if you see areas in which they could improve.
- I would also say that it is important not to be seen to challenge their diagnosis, but just to ask whether what you have researched is relevant. If your doctor refuses to consider what you have researched (as opposed to explaining why it is not relevant), do not be afraid to get a second opinion.

Acknowledging Limits

It is important to be realistic about the situation and what is possible. Doctors are people too and they have to work within the System.

- Accept that the doctor needs to stay within professional guidelines.
- What I learned is that doctors do not know everything and we should not expect them to.
- Realize doctors are human and that they probably have to deal with a lot of not very bright people all day long.
- You respect a GP for his training, but you should keep it in perspective. If he knew everything, there would be no need for specialists. You also have to remember he cannot be up-to-date with everything and a lot of his post-graduate education comes from seminars run by drug companies, who have an agenda of their own.
- I remember the comment that my sister made once – her doctorate is in languages, she has a medical doctor husband, two medical doctor sons, a dental consultant son and an orthodontist daughter. At a particularly fraught time in my wife's struggles with Multiple Myeloma, my sister urged me to remember that all of the prognoses expressed by doctors were simply the words of a man/woman – albeit a trained, experienced man/woman – and no more! In short, my advice to anybody dealing with the medical fraternity would be not to place these individuals on a pedestal – they just might fall off!

Establishing Rapport

Establishing a rapport is based on acknowledging that you are two people in a difficult situation – you are ill and the doctor is busy – but if you can help each other politely, you will both benefit.

- A helpful and enquiring, not aggressive, attitude.
- To get the best out of a doctor, we usually have to walk in looking for something to learn.
- Be friendly and firm, ask to have the whole thing explained to you (causes and effects of your illness, where applicable, your treatment and overall prognosis, given various factors).
- I'd suggest establishing rapport with the doctor, paying them a compliment and then displaying knowledge by dropping some general medical terms and specific medical context into the conversation, so the doctor knows you are a more 'interesting' customer than usual.
- Try to get information, use it politely in such a way that the doctor knows he/she is not dealing with a jerk so he/she must be professional, but letting him/her know that the doctor is not you.
- Try to really talk with your MD and open up and try to show him who you really are in mind and body.
- Don't compete – it's not a level playing field. You're sick and doctor has the know-how you need.
- Don't expect other smart people to appreciate your gifts. If you're going to tell your doctor, don't do it during a stressful situation and expect it to help. But I would say the same thing about telling your accountant you are smart!
- If the doctor is not listening, you can use your network to get heard next time. When I said to my ENT specialist and to my former lung specialist (whom I met coincidentally in the hospital) that I found the 'communication quite difficult'. They both spoke with him and after that the communication became much better.

Focus & Clarity

Both the patient and the doctor have limited time and energy, so stay focussed on the most important aspects. Then persist until you are both clear about what is happening and what you are going to do.

- Stick to being clear and focused in your communication.

- Don't waste doctors' time. I find if you only focus on what you really want to know, they will always take your questions seriously.
- Keep everything you say about your medical issues as simple and clear cut as possible. No ifs and buts, just the simplest, clearest message you can give, focussing on the bits that are the biggest problems.
- Now I tell them what my symptoms are, what my experiences are with treatments and medicines (sometimes not) and what my preference is. At the moment, my doctors suggest examinations and tests I had to ask for in the past. It feels good to be supported.
- Pretend that both of you are 12-year-olds and communicate on this basis – no long and fancy names, yelp if they poke something that hurts, put on a sad face when you're ill (including in the waiting room).
- Go with an open mind, clear description of your problems and let the doctor do the questioning.
- Do not hesitate to question things with the doctors if you are not sure or want more information.
- Ask questions and keep asking until you feel that you fully understand what is happening.

Sort out any ambiguities

- Say you don't know what that means. We don't have to do that often and it doesn't come naturally. But no-one knows everything and besides, it appeals to doctors' arrogance and at the same time lets them have the pleasure of explaining to someone who can understand. This can get you more attention than most people.
- Ask your MD to interpret the info he/she gives you – help you understand how serious or not serious something is. Ask for help in knowing what physical symptoms to ignore or take lightly and what ones are serious enough to seek medical attention/intervention.
- When you're facing big medical stuff, take a trusted family member or friend with you to listen, make notes, ask questions also.

Communicating

Be tactful – you are the one who wants something and you are the one who will suffer more if you don't get it. Give reasons for your ideas, employ the power of suggestion and repeat as necessary.

- Be careful in the way you ask questions. My experience is that looking curious and interested brings more answer and sympathy than an inquisition question style, even if you see a lack of competency.
- I would contend that personality, loads of direct exposure to 1:1 communication and some degree of involvement do the trick.
- Rather than solving the problem for the doctor, I'd suggest leading questions, such as: "Do you think this would be better than that?"
- Asking tactful questions.
- The 'opinion' could have been phrased more tactfully as a question.
- The first time you use a technical term, follow it with the equivalent everyday term in a rising tone, asking for confirmation. It helps if you both mean the same thing when using medical jargon and phrasing it as a question does that smoothly. It sets a tone of equals looking to communicate well, so it is more likely to be seen as checking a meaning for clarity than as competitive or arrogant.
A doctor who confirms with a nod or a word without skipping a beat is likely to work with you as a partner. A doctor who tries to take you down a peg or two or trip you up to establish dominance probably won't.
- Have a good reason for your proactive attitude – nearly dying is a good one, but having had a parent misdiagnosed or some such works too.

- There is a big difference between expressing a preference and giving advice or, worse, orders. Anything that might be perceived as 'telling the doctor what to do' can get a bad reaction. With some doctors, having a good reason is enough. "I would like to try such-and-such, because it worked in the past" or "because it worked for so-and-so who has the same problem" or make an appeal to authority, such as a medical journal or university that also recommended your idea. More status-conscious doctors require more subtlety and the power of suggestion can work wonders with them. Plant the idea and then hope they run with it: "have you heard about?" or "what do you think of?" or "I read about such-and-such. Do you think it would suit my situation?"
- Practice, practice, practice if you are not a born and raised communicator.
- Sometimes the power of the argumentation is in repeating or in course of time. "Would you please think about it." Or let it go wrong. That's a worse choice.

Notes & Research

Prepare for consultations and make written notes, both to ensure that the agenda includes everything of importance and to keep track of progress.

- Take time to prepare for each visit, conduct research from credible resources to fully understand your situation.
- Prepare well for appointments, so you can talk about things you may have investigated/found yourself.
- My advice is to use the brains God gave you and do your own research.
- Trust your own judgement when you've done enough research to verify it.
- A gifted adult should keep well informed about his or her health problems and be aware of the side effects of any medication they are given.
- Write down all your questions.
- It may be an idea to make a note of the questions you have on paper, and acknowledge to the doctor that you have a lot of questions, but that you would be happy to give him/her the list of questions so they can formally respond when you next meet.
- Put your agenda for a consultation in writing. Illness makes us less than our best and usually has adverse effects on the memory, plus modern medicine is subject to time constraints. An agenda helps to make sure all the key points get covered in the time allowed. If you give a copy to the doctor at the end, it will help them write their notes, particularly if they were distracted during the consultation.
- Keep a written log of your symptoms if there is lots to keep track of.
- Where appropriate keep a record of your blood pressure, pulse rate etc. over time. Your GP will find this more useful than vague anecdotes. His only measurements will be on the day and the stress of your visit may affect them.
- Always get copies of your doctor's notes and have them updated if you see a need.
- When searching on the internet, make sure you use reputable sites, not ones with a vested interest (selling you something). Print out what you find and take it with you to your MD appointment.
- Look up medical terminology that you don't know.
- Don't assume your doctor has given you all of the necessary information. If you are taking more than one medication – over-the-counter as well as prescription – check the known interactions. If they miss something, the worst that might happen to them is a slap on the wrist, but the worst that could happen to you is death.
- 'Male intuition is the capacity to oversee the situation in one view and make a fully wrong judgment'. So remember it is possible to make totally wrong conclusions based on information you get from your doctor/ the internet etc.

- More people should read *Your Medical Mind* by Jerome Groopman (or equivalent) and get much more clear about how their own history and backstory affects their response to medical information.

Best Practice

Take care of your own health, including the less tangible aspects such as emotions, using all of the skills at your disposal.

- Take charge of your own health in a pro-active way.
- Do what you can yourself to stay healthy – perhaps above all, keep your weight down.
- Give your body/mind the care, sleep, rest, relaxation, stimulation, nutrition, exercise, etc. that it needs.
- As informed consumers, we need to know what our options are and don't rush into decisions that will impact the rest of your life.
- Remember the mind/body connection.
- Combine feeling, facts and knowledge.
- Express and process your emotions so that your body does not stay or become the container for them.
- Take into account your gifted characteristics – your acute awareness, high sensitivity, high intensity, etc. – when you describe your symptoms.
- Be conscious of the fact that you may be threatening for others.
- This internal medicine specialist thought being self-willed is a good characteristic for someone with a chronic disease.
- Keep a healthy sense of scepticism about psychology and psychologists.

4. Advice for Doctors

What is your advice for medical doctors?

Respect, Acknowledging Limits, Assumptions, Listening, Questions & Explanations, Medical Jargon, How the Gifted are Different, Best Practice, Other Ideas

Synthesis

Alice Burkin, leading US medical malpractice lawyer, says: "What comes up again and again in malpractice cases is that patients say they were rushed or ignored or treated poorly." She also noted: "When a patient has a bad medical result, the doctor has to take the time to explain what happened and to answer the patient's questions – to treat him like a human being. The doctors who don't are the ones who get sued." Here is a summary of the advice that multiple respondents mentioned or alluded to, which corresponds with Alice Burkin's conclusions (in Gladwell, 2005):

Have respect and empathy – bear in mind that the patient is a human being with feelings.

Listen and observe, gather as much information as you can before coming to a conclusion. If you do not trust the patient, they are unlikely to trust you. Be clear & concise – explain how the treatment works, what to expect and under which circumstances to make a follow-up appointment.

Respect

The foundation of all good relationships. Patients are people too, not just collections of symptoms.

- Respect others and their intelligence or ability to learn.
- Respect (given & expected) – patients are not a sub-species.
- Deal with each other on an equivalent level.
- Treat your patients as a whole, not as a series of symptoms that can be treated separately.
- Care: don't forget your patient is a human being with feelings.
- Whenever possible, sit down instead of standing over a patient. Be one human being talking to another.
- Take your patient's perspective seriously.
- If you disagree with their ideas, be willing to tell them why – in a person-to-person, equal-to-equal way.
- Be open and honest with patients.
- Work in partnership with your patient. Remember that you have knowledge and skills the patient doesn't and vice versa. If you can work in partnership, it will produce the best outcome, as you can leverage both your strengths.

Acknowledging Limits

Both patients and doctors have limitations that must be taken into consideration if the outcome is to be successful.

- You should accept that you can make mistakes.
- When you are not capable of dealing with a case, say it and don't be too proud. Especially when the patient already arranged input from professors, please make use of it.
- If you do not know all the details, there is nothing wrong with saying, "I cannot answer that for you right now, but I will get the information and come back to you." Most gifted people will recognise that this is not a poor reflection, but a consequence of you having to have knowledge of a vast amount of medical information.

- You can never be right up to date about everything and most gifted people will realise this and not judge you on it.
- Be aware of your beliefs about roles. Have you ever explicitly examined your idea of what a doctor is & does and what a patient is & does? If your ideas are, broadly speaking, that doctors are active & superior, while patients are passive & inferior, you're going to insult & annoy any patients who don't fit your stereotype and many who do.
- Never forget the 'law of unintended consequences'. The patient a doctor disrespects today may be the traffic-warden you meet at your badly-parked car tomorrow or maybe the dentist you next visit in your urgent need.
- However gifted the patient may be, you are the one with the training.

Assumptions

Don't make assumptions, particularly derogatory ones – it's unprofessional.

- A doctor should never treat a patient like a fool.
- Don't assume the patient is a liar or mistaken. If your next move is not to bother with an examination, tests or a proper diagnosis, that assumption is designed to reduce your workload at the patient's expense. Remember you swore to do no harm.
- Don't make assumptions.
- You don't know who I am or what my capabilities are. Try speaking at a higher level and then dumb it down if necessary.
- It is difficult to judge a person's intelligence. You are more likely to under-estimate it than over-estimate it, so don't try.
- You should accept that your patient can bring you some ideas you didn't think of.
- They may benefit from my knowledge/expertise and intuition. That they should not reject that immediately.
- Be wary of being judgemental. You don't what kind of life your patient has led.
- Professionals generally assume that they know best and are not used to having their competence challenged. Gifted people don't generally walk in with a certified IQ badge, so there is (a) the message that this client is worth listening to and (b) the professional's ego to deal with.
- A lot of folks lie about things they find embarrassing, such as how much they eat, drink, go to the toilet, exercise, smoke, have sex ... Don't assume they will have make the connection that being 'economical with the truth' will make it far less likely that the treatment will be appropriate & therefore effective. It may help to point out that the truth, the whole truth & nothing but the truth will help make the correct diagnosis & select the correct treatment. Yet that will only work if you can then avoid showing them any negative judgements if they do tell you the truth.

Listening

This key skill is the foundation of a consultation and was highlighted by the vast majority of respondents.

- Listen to your patients.
- Really listen.
- Listen carefully to what your patient has to tell you. Give them time to explain, in their words, what is their problem and to ask questions.
- Listen. Don't discount the patient's self-knowledge.

- I bring first-hand knowledge of symptoms and results.
- Sympathetic listening and explanation (where appropriate) will engage them as a partner.

Questions & Explanations

Asking and answering questions clearly is a vital part of the consultation and treatment process, as well as common courtesy. After all, both parties are aiming to learn something.

- Be willing to listen, ask questions, answer questions and take into account your patient's or their family members' knowledge and ideas, even if they are "out of the box".
- At least have these ideas responded to with intelligent answers, and not be dismissed without a reasonable, intelligent, human, courteous response.
- Ask the patient questions that are easy to answer because they suggest the sort of answer you are looking for. "Can you point to where the pain is strongest?" "What sort of words would you use to describe the pain, for instance sharp, throbbing, incessant, achey?" and "Does it feel more like it comes from your muscles or your bones or somewhere else?" are all good questions.
- Do not feel undermined by a patient asking a lot of questions. It is not to question the authority or knowledge of the doctor, but mostly the patient aims at getting peace of mind or putting themselves at ease.
- Present explanations for your suggestions and recommendations.
- Explain the cause and effects of the disease and the treatment.
- They may live longer when they actually understand your instructions.
- Adherence – Explain how the treatment works, so the patient knows how their actions can help or hinder the process.
- If they show poor adherence to treatment, don't just assume, but ask them why.

Medical Jargon

Be aware of the difference between common knowledge and specialist jargon. Language is better used to clarify rather than confuse.

- All people who live and breathe with some special jargon come to take it as natural. They forget that everyone doesn't speak that language. Even smart people.
- Translate medical-ese into everyday language.
- Practice saying things in common terms that regular people use.
- Use metaphors and analogies.
- These days, I spend much time interpreting for patients who have no idea what their doctor said. They are embarrassed to say so to the brisk doctor, so they ask us 'regular people' in the lab.
- Make sure you agree on the meanings of technical terms before you start using them. People who were punished for questioning authority in childhood tend to be reluctant to say when they don't understand. Watch your patient's face and if they look puzzled or frozen, deliberately check which bit they didn't understand.
- If a patient knows medical terminology relating to their problem, subtly check they really understand the word they're using (preferably by asking things like "just to check, by urethra, you do mean the canal that you urinate through, don't you?" rather than the sort of question designed to bring school children down a peg or two). Don't try and test how far this knowledge extends.

How the Gifted are Different

In an article from 2016, O'Hara and Lawson state that patient involvement in patient safety is a challenge and a future opportunity. Diversity is a fact. Patients have very different needs. We think that gifted patients are the patients who already try to get involved. Their characteristics seem to us the ones that will get healthcare to a higher level.

- You need to understand gifted intellects and their personalities in order to engage them. They are normal people, just MORE so in some ways.
- Remember, the gifted are always gifted. They didn't ask to be like that. Some of them hide it, but actually you're better off if they feel neither the need to hide it nor to show it off.
- Be aware that not all of the gifted have much in the way of social skills, though, so the "fascinating puzzle" approach works better on average than using typical "people skills".
- Engage the patients in discussion and respect their need to more fully understand their condition.
- If you have a gifted patient, they are going to do their own research. Do not undermine what they have researched, since it is highly probably that they could have found something pertinent.
- They will ask a lot of very technical or detailed questions.
- He has to accept that a gifted person is his own director.
- A gifted patient will recognise they're being tested or competed with and it will turn the relationship into one neither of you wants.
- Don't feel threatened by them – they're used to everyone else remembering less than they do and not knowing everything. You don't need to prove you're better than them for them to find you a good doctor. All you need is for them coming to you to be an improvement for them over what they can do on their own.
- Never use "appeal to authority" as a reason for doing something -- "because I'm the doctor" is guaranteed to get sub-par results from these people.
- If you learn that a patient has intellectual gifts, try to use them in the management of their health.
- They will be willing, very trainable partners in their own treatment and they have a better overall prognosis than others, because when they know why they are doing a treatment, they do it wholeheartedly.
- I would say that they need first to be made aware of the link between giftedness and some ailments – depression etc. – before they are given advice on how to support gifted patients. I feel that Occupational Health professionals should also be included in a program to increase awareness of these issues.

Best Practice

- Doctors have to understand the patient and not the other way around.
- As an MD, try to get really good insights in human behaviour and thinking.
- Take some courses on interpersonal psychology and team interaction, so you can make it work.
- Decide which is more important: to practise medicine well or to prove that you have higher status & are the sole arbiter of medical knowledge. It is very unlikely you can do both simultaneously.
- Take your time to really know them at first intake. Put in his medical file your findings of the type of patient and change or improve the profile of the patient accordingly over time.
- Without a good diagnosis, treatment is likely to be hit-or-miss. Make sure you get a full explanation of the symptoms, asking questions where necessary, and find out about any relevant history before making a diagnosis. Don't guess something common & convenient after the first sentence.
- Work as hard as you can to come up with the most accurate diagnoses you are able to.

- Relate objective evidence in your office notes. Properly document what is needed for insurance companies and government assistance.
- Offer credible resources for further education, so that “the Internet” doesn’t become the only source.
- They should keep their clinical training up to date. Read up on cases.
- Holistic treatment is important. The mind & body interact and each part affects the others. The practice of seeing patients as a collection of parts & symptoms is dehumanising and reduces trust. Patients want to know that the doctor cares about their well-being and sees that they are coping with all of their symptoms as a whole. Separating symptoms also means that co-morbidities are ignored. They will treat the back-ache, but not the leg injury that caused it, because that’s somebody else’s department. If the lynchpin is identified, the treatment is more likely to be successful.
- Consider strongly how few cancer patients will ever find their conditions improved by chemotherapy.

Other Ideas

- Appointments systems are organised for the convenience of healthy doctors, not what sick patients can manage. Unsurprisingly, people miss appointments because they are too ill to jump through the hoops at the specified times. Illness doesn’t run to a timetable. Instead of complaining & putting up notices, perhaps they should redesign the system in a more patient-friendly manner.
- Allergy-testing – It is better to find out you’re allergic to peanuts after eating one than a whole packet. It is the same with new medications. An allergy-testing dose would need to differ according to the action & mechanism of each type of medication. Obviously, it would be inappropriate in emergency situations, but very appropriate for minor & chronic conditions. Developing allergy-testing doses for each type of medication would save a number of potentially dangerous adverse reactions and save a lot of money on wasted prescriptions. If you have been given enough for a month or 3 and the first dose prompts an allergic reaction, it is likely that the rest of package will be thrown away or stuffed in a drawer.

Consultation Agendas

It might be useful to have 2 template agendas for consultations – one for diagnoses & another for treatments. Below are broad suggestions for what might be included in general practice consultations and could also provide a rough template for specialists writing illness-specific agendas.

Diagnosis Agenda – a list that the patient or doctor can make notes on or just use as an overview. The aim would be to ensure that all the key points are covered – patients might be unsure what is relevant, particularly when differentiating between similar groups of symptoms that require different treatments, such as a new or typical headache, diarrhoea with cramps or with vomiting or with a sickly sweet smell and so on. The acknowledgement of how much the illness is affecting a person's life is also an acknowledgement of them as a human being in distress.

The Treatment Summary ensures that the patient has a note of what they need to do afterwards. When people are ill, and particularly if they have just received worrying news, they are less likely to remember details. Having notes they can refer to later would be helpful for adherence and engages them as a partner in the healing process.

Diagnosis Agenda

Is this illness: **New** a **Flare-up** of an existing condition a **Continuation** of the same condition

How much is it affecting your life?



What body part(s) &/or function(s) is your illness affecting?

Is it affecting your: Energy levels, Pain levels, Sleep, Body temperature, Appetite, Digestion, Going to the toilet, Mobility, Mood, Social/Work functioning, Other?

Do you need any paperwork for other organisations? forms, reports, certificates, referrals ...

Treatment Summary

A template on which the outcome of the consultation is noted as an aide memoire and a to-do list:

Paperwork: prescription, test, appointment, form, certificate, report ...

Monitor: what to pay attention to & under which circumstances to make a follow-up appointment.

Interactions: are you taking any other medication(s), including OTC drugs?

Treatment: what, how much/many, when, with IE 3 a day with meals, rub on when it hurts etc.

Behaviours: a note of what the patient can do to aid healing, IE bed rest, exercise, eat extra, eat less, hot baths, cold showers, rinse with salt water, keep dry, get regular blood pressure readings, research nutrition, get hypoallergenic pillows, arrange for someone else to walk the dog etc.

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