

*Communication*



## **International Patient-Provider Communication Newsletter**

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[www.centralcoastchildrensfoundation.org](http://www.centralcoastchildrensfoundation.org)

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### **Special Issue on Preparing for Medical Encounters**

*[Editor's Note: This special edition of the International Patient-Provider Communication Newsletter is devoted wholly to the topic of preparing people who are especially vulnerable to communication breakdowns during medical encounters to do their part in helping navigate the communication barriers that occur so frequently for this population. It is addressed both to the patients themselves, to their family members and advocates, and to the people who serve them in a wide variety of professional roles, from classroom teacher to physician. We have tried to focus on practical solutions in real-life situations, and to emphasize low-cost and no-cost ideas and resources. As with curb-cuts and other accommodations for people with disabilities, these resources can often also be of value to the general populace. The Editors]*

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### Introduction

### *PREPARING FOR COMMUNICATION IN FUTURE MEDICAL ENCOUNTERS: IT'S NOT MY JOB?*

Harvey Pressman

Many professionals who work with children and adults with communication impairments and vulnerabilities work outside of health care settings, in schools, independent living centers, vocational training settings, *etc.* The clients they work with almost inevitably confront more frequent medical encounters, emergency room visits and hospitalizations than the general public. When those people experience *these* kinds of medical encounters, they also face a disproportionately large number of communication barriers and breakdowns, which interfere significantly with effective medical treatment. Curiously, not many of these professionals yet acknowledge not only that it is their responsibility to help their clients, but that it's an essential support to the health, education and welfare of the people they help care for.



Fortunately, those professionals who *do* want to help prepare clients for these often crucially important medical and often frequent encounters have available a wide variety of materials that can help their clients prevent communication breakdowns in the doctor's office, the hospital emergency room, the ICU, at bedside in the hospital, at hospital discharge, and in the many other health care settings in which their clients find themselves communication vulnerable, *etc.*

It makes sense, then, that the speech language pathologists, the special needs teacher, the vocational specialists and all those other helpers that work outside of health care settings take some responsibility to help the people they work with navigate future medical encounters more successfully. And there is no need to reinvent any wheels. There already exist lots of ways people have already developed to provide simple tools and strategies that help in these situations: medical communication passports, lists of questions to make sure you get answers to, strategic advice to people with disabilities about dental visits, clinic visits, apps for the iPad, *etc.*, *etc.*

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"More and more patients are going to the Internet for medical advice. To keep my practice going, I changed my name to Dr. Google."

But many professionals who work with people with communication disabilities are unaware of how they can help, and how the skills, tools and strategies they have at hand can be of invaluable assistance to clients who will find themselves in communicatively perilous healthcare situations down the road. Isn't it time for professionals who work outside healthcare settings to acknowledge that it is their responsibility to be more helpful in this area, and to learn more about the strategies and tools that their clients will need during future medical encounters?

While many professionals work with children and adults who have a communication impairment, or communication difficulties secondary to language or cultural issues, *outside* of healthcare situations (*e.g.*, in schools, independent living centers, vocational training settings, community agencies, *etc.*), their clients typically experience more frequent medical encounters,



"The Doctor will see you now. Here's your medical jargon dictionary."

healthcare encounters.

emergency room visits and hospitalizations than the general public. This means they are at risk for confronting a disproportionately large number of communication barriers and breakdowns over time. This can, and often does, interfere with effective medical treatment.

This newsletter will describe the many practical ways that professionals who work outside the health care system can help their clients (and families) be better prepared for these inevitably difficult transactions. It will also provide guidance on how to access the practical strategies and materials that are known to be useful to people with communication vulnerabilities during

## Articles

### *Advocacy for People with Speech Disabilities: Emergency Preparedness Resources*

**By Pamela Kennedy**

*January 2015 Updated and adapted from article originally published in Therapy Times. Kennedy, P. (2011). No One to Speak for Them: Emergency Preparedness Resources for Those with Speech Disabilities. Therapy Times, 14, 15.*

The ability to communicate is crucial in the event of emergencies, such as a hurricane, flood, fire, trauma, or loss of electricity. Emergency personnel need to be able to interact with the individuals whom they are rescuing; medical personnel need to get accurate information from those who have been injured; displaced persons need to contact loved ones.

At these times, no population is more at risk than those with complex communication needs (CCN) - people who have difficulty communicating as a result of pre-existing disabilities such as cerebral palsy, autism, and cognitive delays. To compensate and interact with others, they utilize augmentative and alternative communication (AAC) techniques like speech-generating devices, sign language, and picture communication displays.

Emergencies pose additional challenges for people with CCN because of the absence of familiar communication partners, loss of electricity to power AAC devices, and the need for low-tech speech technology such as displays with vocabulary that addresses emergency issues. However, these risks can be minimized with forethought, planning, collaboration and teamwork. As a person with cerebral palsy who communicates via a sophisticated speech-generating device, sign language, written messages and gestures, life taught me that lesson when I became a refugee during the Grand Forks, North Dakota flood of 1997.



Flooding had been forecast three months in advance. I had served on Grand Forks' Emergency Preparedness Council for People with Disabilities and entered my name, address, disability, and required accommodations in the special needs registry. Doing this insured that emergency call centers across the state had my name, location, disability and accommodations on file in the event of any emergency. Because no one expected my neighborhood to be affected, I thought that would be enough.

But I was not spared. The flood was far worse than anyone expected, and breached the dike on April 19th. I heard the sirens signaling for evacuation around 2:00 a.m., when my neighborhood was already completely flooded and I was trapped. Because there was no one in my home who could help me into my chair, I was helpless for about eight hours until a team of emergency responders came by boat, followed by a National Guard truck to rescue me and my assistance

dog Jessie. They barely had enough time to get me in my chair, and to grab my medications and my computer with text-to-speech software before we were evacuated to a makeshift rescue facility, separated from family and friends.

Despite the disaster and my forced re-location, I continued my efforts at collaboration and teamwork. Once I arrived at the shelter, I saw refugees with CCN who had no means of communicating because their communication supports had been left behind when they were evacuated. While I worked at the shelter to help refugees like myself create basic communication displays on sheets of paper, I realized that we all should have done more preparation before the disaster.

After the flood waters receded, I wanted to advocate for my peers who cannot speak, giving them a voice and highlighting the issues and dangers people with complex communication needs face each day. However, I needed to find groups with the same goals. Since 2005, I have worked with the Rehabilitation Engineering Research Center on Communication Enhancement (AAC-RERC), United States Society for Augmentative and Alternative Communication (USSAAC), the patient-provider communication forum ([www.patientprovidercommunication.org](http://www.patientprovidercommunication.org)), and local agencies to address this need with forethought, planning, collaboration, and teamwork.

As part of a national effort, the AAC-RERC, people with CCN, clinicians, speech, occupational and physical therapists, vendors, developers, parents and professionals that span the AAC industry have worked to develop resources and materials for individuals with CCN for use before, during, and after natural disasters. These include:

1. A special edition newsletter that highlights the need for action, as well as resources and supports.
2. A webcast featuring my experiences as a refugee and recommendations for people with CCN.
3. Ready-made communication pages for use by people with CCN.
4. A list of resources and tips for communicating with first responders and medical personnel.
5. A symbolized children's story to teach students how to build an emergency kit.

I became involved with the AAC-RERC's emergency preparedness initiatives in 2007 after learning that Dr. Sarah Blackstone, an AAC-RERC partner and the President of Augmentative Communication Inc. , was preparing a special issue of *Augmentative Communication News* that would focus on emergency preparedness. The publication explored disasters, AAC industry relief efforts, tips for communication, refugees' stories, and information regarding efforts of the United States government to address disaster relief issues for people with special needs. This resource is available at [http://www.augcominc.com/newsletters/index.cfm/newsletter\\_3.pdf](http://www.augcominc.com/newsletters/index.cfm/newsletter_3.pdf). When that was completed, Sarah Blackstone and I teamed up with Dr. David McNaughton from Pennsylvania State University to create a webcast entitled, "Disaster Preparedness for People



with Complex Communication Needs" for the AAC-RERC website (available at <http://aac-rerc.psu.edu/index.php/webcasts/show/id/12>). The broadcast features the presentation I delivered in New Orleans in 2008 at a conference that addressed disaster relief issues for people with CCN. In it, I shared my experiences as a refugee and highlighted seven steps one can take to insure his/her safety, illustrating them using my own disaster plan. These include:

**1. Carrying a bag of essential items at all times.** Some people with CCN also have swallow disorders that require dietary modifications to minimize the risk of choking. I am one of them. As a result, I always wear a waterproof backpack that contains modified food, flavored liquids, and a special cup designed to address my issues regarding swallowing liquids. My backpack also contains a printout of my medical information, dietary limitations, insurance cards, a small notebook, pens, emergency contacts, doctors, activities of daily living instructions, charged cell phone, inhalers, and pain medication. Carrying these items meets my needs and enables anyone—including first responders and medical professionals -- to learn quickly about my communication abilities, my dietary needs, as well as my normal activities and accommodations. They can then perform any needed assessments quickly.



**2. Making an emergency kit.** I keep a Go-Bag in a closet near an exit. It includes a change of clothes, copies of communication interfaces, medication, medical supplies, animal carrier, and food and pet food in re-sealable, watertight containers. That way, if I ever need to be evacuated again, my family and I are as ready as we can be.

**3. Contacting the local emergency department.** When I move to a new area and emergency management doesn't have a registry, I notify police department and emergency responders that a person with physical disabilities and complex communication needs lives at my address.

**4. Creating a personal disaster plan that identifies and addresses hazards specific to each person and situation.** I've developed a disaster plan with my network of family and friends, so I don't have to rely on emergency responders to rescue me unless absolutely necessary. I am at risk because I currently live in Bismarck, North Dakota in a third floor apartment. Snowfall, road closures and fires pose a huge risk for me. To minimize all of these, I moved into an apartment that is literally right next to the fire station. The roads are cleared on my street before any others in the city. And, if there's a fire in my building, they can see it from the station. Everyone involved in my immediate care group—those I live with, my emergency contacts, caseworkers and attendants—all know my communication techniques, unique medical and emergency protocols and the location of associated supplies and escape routes. When/if there is an

emergency, a list of people who need to be called and things that need to be done so I can communicate in any new environment is available (*e.g.*, pack my speech device with its cord in the case and bring my backup paper communication displays.)

**5. Being aware of potential disasters.** Because I have lived in multiple flood-prone regions, I have learned to monitor weather watches and warnings online.

**6. Having someone call during risky conditions.** When a watch or warning is issued, somebody calls me on a regular basis to see that I am safe.

**7. Being prepared to evacuate.** When flood watches or warnings are issued, I make every effort to be in my wheelchair and with someone who knows me.

The AAC-RERC recognized the need for downloadable ready-made communication boards with core vocabulary for emergencies. Diane Bryen from Temple University worked with adults with CCN and first responders in teams. They created and revised lists of words that they would need in the event of a disaster. and reached consensus on a key set of vocabulary items. Bryen then created the communication boards. The sets are available in English, Spanish and Haitian Creole languages and downloadable from:

- <http://www.temple.edu/instituteondisabilities/aacvocabulary/e4all/EprepPictureAi d.pdf>  
(English version)
- <http://www.temple.edu/instituteondisabilities/aacvocabulary/e4all/EprepPictureAi dES.pdf>  
(Spanish version)
- <http://www.temple.edu/instituteondisabilities/aacvocabulary/e4all/EprepPictureAi dCREOLE02010.pdf> (Haitian Creole).





The AAC-RERC collaborators took a similar approach and developed three in-depth guides to address specific areas of concern for people who use AAC. The first, *"Emergency Communication for People Who Have Limited Speech"* provides a step-by-step-guide for developing personal disaster plans with questions to help identify an individual's unique needs and hazards. The second, *"Emergency Communication for Emergency Response Personnel"* educates medical professionals about those who utilize alternative communication strategies and facilitates interaction. It contains commands and questions for the communication partner, such as, "Listen and watch carefully," and, "Show me how you say 'NO.'"

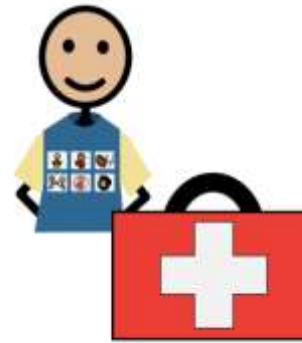
The third guide encourages adults to advocate for emergency preparedness on behalf of those who have communication disabilities in their own communities. These resources are available on the web at <http://aac-rerc.psu.edu/index.php/pages/show/id/4>. Finally, the AAC-RERC and I felt it was important to create resources that educate children about disaster readiness. As a result, I forged a partnership with Sarah Blackstone, Pat Ourand (a former USSAAC President), Theresa Tanchak, Education Consultant at Region 4 Education Service Center in Houston, Texas and *News-2-You*, a publishing company that produces symbol-based publications for use in special education classrooms. Jacquie Clark and Allison Shumaker from *News-2-You* also enabled me to write, *"Billy Builds a Kit,"* a symbol-based story designed to teach the importance of emergency preparedness issues for people with CCN. It can be downloaded from <http://aac-rerc.psu.edu/index.php/files/serve/id/38> (English text) and [http://aac-rerc.psu.edu/documents/billy\\_builds\\_a\\_kit\\_supported.pdf](http://aac-rerc.psu.edu/documents/billy_builds_a_kit_supported.pdf) (symbol supported text).

Preparing for emergencies and natural disasters is crucial for adults and children. Those who have difficulty communicating as a result of pre-existing disabilities are especially at risk because of the potential loss of familiar communication partners, communication displays, and speech-generating devices that require electricity. However, the risks can be minimized with

forethought, planning, collaboration and teamwork.

Working with the staff and partners at Rehabilitation Engineering Research Center on Communication Enhancement (AAC-RERC), the patient-provider communication forum, United States Society for Augmentative and Alternative Communication (USSAAC), News-2- You, and the Pennsylvania State University, I have worked to help develop multiple materials to address the need: a special edition newsletter that highlights the issue with a call to action, a webcast featuring my experiences as a refugee, ready-made communication pages, a list of resources and tips for communicating with first responders and medical personnel a symbolated children's story to teach students how to build an emergency kit. Communities need to educate people, build networks, and share information. People with complex communication needs need to use their speech technology and become advocates. Please check out these resources and do everything possible to prepare.

## Billy Builds a Kit



## Difficult Conversations

by Harvey Pressman

***[Author's note: Many physicians who write about patient communication comment on how difficult end-of-life conversations are for most doctors. The same is true for most patients. So it is hardly surprising that everybody, patients and doctors alike, has trouble having clear, meaningful conversations around end-of-life issues. Add to the equation a patient who enters into such a conversation with a communication impairment, or somebody who is communication vulnerable for one of many other reasons in a high-stakes medical interaction, and you have a sure-fire formula for communication breakdowns. In the essay below, I try to make clearer and more explicit the questions patients may need to raise even when their doctors don't, and I advocate for "pre end-of-life" conversations earlier and not waiting until one's days have dwindled down to a precious few.]***



"I'm dying to ask you some questions, Doctor," the hospice patient remarked to the visiting physician. "Well...", the Doctor replied, "uh... perhaps we can take those up on my next visit."

"No," said the patient, "I mean it's clear that I'm literally on a downslide to death, and I think I'd better talk about some questions and some issues about my demise sooner rather than later."

This kind of conversation rarely (if ever) happens, but it needs to happen a lot more frequently than it does. Often, the patient will have to be the one to initiate the end-of life chat, because of the reluctance of many physicians to raise such questions, or to address them very comfortably or comprehensively. (Atul Gawande, *Being Mortal*, 2014)

In his recent book, *The Conversation*, Dr. Angelo Volandes profiles seven critically ill patients, including his own father. Through their stories, he drives home the importance of doctors talking to patients about how they want to die. He admits these conversations are hard, but he says physicians need to be asking their patients six questions; and if doctors aren't asking them, then patients need to take the lead. The questions?

1. What kinds of things are important to you in your life?
2. If you were not able to do the activities you enjoy, are there any medical treatments that would be too much?
3. What fears do you have about getting sick or medical care?
4. Do you have any spiritual, religious, philosophical, or cultural beliefs that guide you when you make medical decisions?
5. If you had to choose between living longer or having a higher quality of life, which would you pick?
6. How important is it for you to be at home when you die?



Volandes co-founded Advance Care Planning Decisions, a nonprofit organization aimed at educating patients and their families about the options for end-of-life care using short, high-quality videos.

Volandes started out developing these videos in his living room with his wife and various family members and friends playing the roles of patient and physician, working through common questions he heard from patients in his practice, and also showing physicians how to ask tough questions (his wife didn't need to act; she is a physician, too). The videos have become such a popular training tool that shooting moved to a real studio.

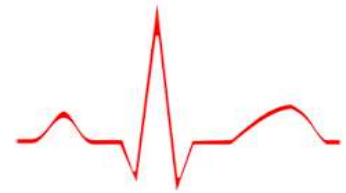
<http://www.acpdecisions.org/about/>

In a similar vein, renowned author and physician Atul Gawande writes precisely and profoundly about the medical issues many other physicians ignore or avoid. In his most recent book, *Being Mortal*, Dr. Gawande includes a chapter called "Hard Conversations," in which he

describes some of the questions he felt compelled to ask his father (also a surgeon) when his dad was clearly dying.

Translating the *questions* Volandes and Gawande raise into *statements* a patient might make to a doctor, the list might look like this:

1. Can we talk about the kinds of things that are important to me in my life, and that might influence how I choose to die?
2. If I were not able to do these particular activities that I enjoy, there are some medical treatments that might well be too much for me.
3. Can I share with you some fears I have about getting sick or about the medical care I might receive?
4. I have some (spiritual),(religious), (philosophical), and/or (cultural) beliefs that will guide me when I make medical decisions, and I'd like to tell you about them.
5. If I had to choose between living longer or having a higher quality of life, let me tell you how I would you decide.
6. Can I explain to you how important it is for me to be at home when I die?
7. If my condition were to worsen, here are some of the goals that would be most important to me.
8. Can I clarify for you what tradeoffs I am willing to make and not willing to make to try to stop what may happen to me? <http://www.acpdecisions.org/about/>
9. Can we talk about the point at which life would become so intolerable to me that I would rather die.
10. May I explain what I think I understand about what may be happening to me, and what would be my fears if these things should?



All of these questions are of obvious relevance to the difficult issues that must be confronted at the end of life, but are those difficult waning days the best time to *start* the conversation? Aren't there too many times when these conversations start too late, and cover too little? Shouldn't patients who want to avoid the awful end-of-life scenarios we hear and read about initiate earlier conversations designed to clarify some issues before they are too medicated to think carefully, too fragile to pursue difficult topics with sufficient vigor, too communicatively impaired to participate equally in the conversations?



Most of the literature about end of life planning focuses on the final weeks of life, when death is imminent and people who are dying are trying to find ways to preserve their dignity and maybe make things a little easier for the people around them. The questions that doctors ask patients at this final stage are all important and immediate, but wouldn't it make sense for individuals, when they have maybe reached something like 90% of their estimated life expectancy, to outline some of the ways in which they would like to negotiate these final days and weeks some years *before* their expected expiration date? And might it not make sense for physicians to find ways to facilitate that earlier conversation?

**Bibliography:** The articles cited in the bibliography below describe some efforts to improve end-of life conversations:

1. Gawande, A. (2014) *Being Mortal, Medicine and What Matters Most in the End*. Metropolitan Books, N.Y.
2. Keeley MP, Koenig Kellas J. Constructing life and death through final conversations narrative. In: Harter LM, Japp PM, Beck CS, eds. *Narratives, Health, and Healing: Communication Theory, Research, and Practice*. Mahwah, NJ: Lawrence Erlbaum Associates; 2005:365-390.
3. Keeley MP, Yingling JM. *Final Conversations: Helping the Living and the Dying Talk to Each Other*. Acton, MA: VanderWyk & Burnham; 2007.
4. Rauch, J. How Not to Die, Angelo Volandes's low-tech, high-empathy plan to revolutionize end-of-life care . *The Atlantic*
5. *Jim Molpus*, Case Study: Advance Care Conversations, *HealthLeaders Media* , May 17, 2013
6. Welch, L. C., Teno, J. M. and Mor, V. (2005), End-of-Life Care in Black and White: Race Matters for Medical Care of Dying Patients and their Families. *Journal of the American Geriatrics Society*, 53: 1145–1153. doi: 10.1111/j.1532-5415.2005.53357.x
7. *Letter Project* [Video]. (2015). Stanford Medicine. <http://med.stanford.edu/letter.html>

## *The Tools of the Trade: Available and Easily Accessible Resources That Can Help Prepare for Future Medical Encounters*

There are a large number of tools available to help you prepare for future medical encounters. We have selected some of the most vital and user-friendly ones.

### **A&E Communication Passport**

The link below leads to an article about free downloads and a Communication Passport that use Widgit symbols. Designed for use in Accident and Emergency situations, the Communication



Passport can also come in handy in other medical settings. The Passport contains three sections:

- Things you must know about me (Red)
- Things important to me (Amber)
- My likes and dislikes (Green)

<http://www.widgit-health.com/downloads/A-and-E-passport.htm>

### **Hospital Discharge Checklist**

This checklist is designed to ensure that a child's discharge plan from the hospital is complete. Time with healthcare professionals is limited and they do not always communicate all of the information to patients. It can be used electronically or in print.

A screenshot of a 'Hospital Discharge Checklist' form. The title is in blue. Below the title, it says 'Use this checklist to make sure your child's discharge plan from the hospital is complete. Note that some questions many not apply.' There are six checkboxes with corresponding questions: 1. Have you received written information about your child's current condition? Do you understand it? 2. Have you been trained on how to care for your child's special needs? Do you know how to care for your child in the case of an emergency (such as CPR, first aid, and other emergency care)? 3. Do you have prescriptions for all of your child's medications and services? 4. Have you been told about public benefits and services, and how to get them? 5. Have you had a discharge-planning meeting? 6. Has a home health care agency been identified? Has nursing coverage been confirmed?

[http://www.medicalhomeinfo.org/downloads/pdfs/Discharge\\_Checklist-MA.pdf](http://www.medicalhomeinfo.org/downloads/pdfs/Discharge_Checklist-MA.pdf)

### **Patient Journal App**



The Josie King Foundation has created a Patient Journal app. Patients and families can use this app to easily record vital medical information, stay organized, keep a permanent medical record, and share the notes with doctors or anybody else via email. Available for free download on the Apple iTunes App Store:

<http://itunes.com/apps/PatientJournal>

<http://www.josieking.org/page.cfm?pageID=86>

### **Access to Medical Care Training Package**

The World Institute on Disability has created a training package on access to medical care for those with disabilities. This package includes an annotated list of 40 publications divided by themes such as health access and long-term services, international development and disability, and women with disabilities. The package also contains two videos, each accompanied by a

training guide. One video and training guide focuses on people with developmental disabilities and the other focuses on people with physical disabilities.

Both sets of videos and guides are designed to train medical providers, families, and individuals with disability to achieve accessible, appropriate care in compliance with U.S. disability law. Both videos use interviews with disabled individuals, family members and a range of health care providers to help achieve this purpose. Finally, this package includes a training tools packet that contains a workshop design and reference material. The workshop design focuses on access and communication in addressing healthcare disparities for people with disabilities. The workshop design also addresses culturally competent care and compliance with U.S. disability law. The workshop design can be used in conjunction with the two videos.

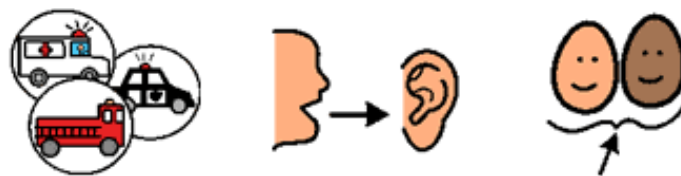
The publications list ([view here](#)) and training tools packet ([download here](#)) are available for free on the website. Most other publications are available for free download on the website, while some are available for purchase. Each video, with its accompanying report, costs \$100 (\$108.75 for California residents) plus \$4 shipping and handling. Purchasing both videos, with their reports, together costs \$150 plus shipping and handling. ([Order here](#)).

*Financial aid is available for those with disabilities or special circumstances.*

[Publications list: <http://wid.org/publications> ; Training tools packet: <http://wid.org/publicationswid.org/publications/access-to-medical-care-training-tools-for-health-care-providers-disabled-patients-and-advocates-on-culturally-competent-care-and-compliance-with-disability-law/> ; Order form: [http://wid.org/publications/downloads/publications\\_order\\_form.doc/view](http://wid.org/publications/downloads/publications_order_form.doc/view)]

#### **Communication 4 All in English, Spanish and Haitian (Creole) (Freely downloadable Temple University communication boards)**

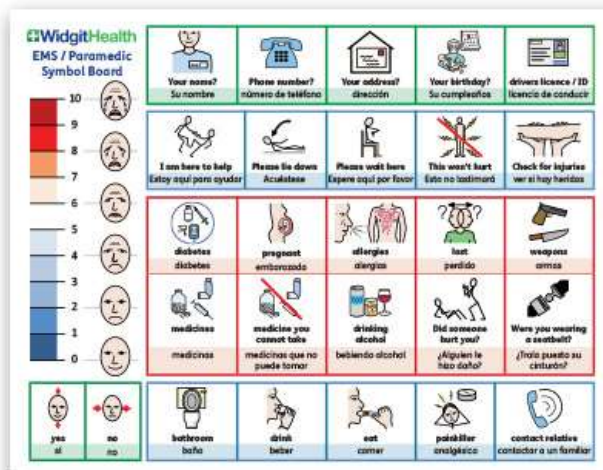
Communication during times of emergency is critical. However, many individuals may not communicate effectively due to their disability, injury, or shock. For others, spoken English may not be effective as well.



Since communication is so important, Temple University has developed free downloadable communication aids in English and Spanish. These aids can be used during times of emergency when spoken English or Spanish may not be effective.

<http://disabilities.temple.edu/aacvocabulary/e4all.shtml>





### Paramedic & EMS Symbol Board (Widgit Health)

Developed with SPEAK Unlimited Inc. This symbol communication board was created as a tool to assist Paramedics and those in the Emergency Medical Services in interacting with any individual for whom clear speech is difficult or impossible. Available in British English and dual-language American / Spanish.

<http://www.widgit-health.com/downloads/paramedic-board.html>

### Tips for First Responders (5<sup>th</sup> edition)



Tips for First Responders (5<sup>th</sup> edition) is a 15-page, color-coded, laminated 4.5 x 5.5-inch field guide, incorporating “tip sheets” that provide information that first responders can use during emergencies as well as routine encounters. They are not meant to be comprehensive, but contain specific information that can be read quickly either before or while responding to an incident, and can be downloaded free or purchased in laminated field guide form. Tips are included for persons with a wide range of disabilities, as well as Seniors, People with Service Animals, People with Mobility Challenges, People with Mental Illness, Blind or Visually Impaired People, Deaf or Hard of Hearing People, People with Autism, People with

Multiple Chemical Sensitivities, People with Cognitive Disabilities, and Childbearing Women and Newborns. May be purchased on the website (Laminated copy suitable for EMC vehicles @ \$5.75), or downloaded in English and Spanish for free at:

<http://www.cdd.unm.edu/dhpd/tips/tipsenglish.html>

### Language Identification Flashcard

<http://www.lep.gov/ISpeakCards2004.pdf>

7 Traditional

## Emergency Medical Situation Communication Board

at the first point of contact in an emergency medical situation in Queensland, Australia.

symbols to help explain what might happen next.

This tool is free, and can be downloaded on a single, double-sided 8.5x11" sheet.

You can download it at: <https://www.qld.gov.au/disability/community/communicating/>



## The Toby Churchill Basic Communication Board



The Toby Churchill Basic Communication Board contains the letters of the alphabet, common words and emotions. The PDF offers 4 choices of keyboard – QWERTY, qwerty, ABCD or abcd. Just make your choice print it yourself, and you are ready to go, it's totally portable and it is best to keep it handy at all times. You could also laminate it in order to make it sturdier and longer lasting. If you lose or damage it you can just print out another. It is a useful item to keep for first responders, in critical care units, doctor's surgeries, schools, day centres, hospices, private homes. It can be used by anybody literate who is unable to speak such as people with vocal cord damage, swallowing difficulties, stroke survivors, MS, MND, Cerebral Palsy, Autism, Parkinson's disease, dyspraxia and other conditions affecting speech. It is also useful when communicating with people with hearing problems.

<http://www.toby-churchill.com/news/free-downloads-and-support-alphabet-communication-boards/>

### **Working with Doctors: A Parent's Guide to Navigating the Health System**

Created to help parents become effective advocates for their children in the health care system. It focuses on communication skills with medical professionals, maintaining records, and other important issues. See Translations for Hmong and Spanish.



An individual copy is \$8 and 10+ copies are \$6 each. Order at:

<http://www.pacer.org/publications/health.asp>

### **Medical Encounter Communication Collection for Individuals**

If you or people you know might sometimes need communication supports in high-stakes situations, medical encounters can be an especially difficult challenge. Too many of them result in communication breakdowns that impact negatively on patient outcomes. There are, however, some fairly simple ways to help make these interactions less likely to fail. The link below connects to a collection of resources that can help make these situations lead to more successful communication exchanges. These mostly free resources include communication boards in many languages and formats, checklists and information to help prepare for a visit to the doctor, and health passports to keep medical information organized and handy.

[http://www.patientprovidercommunication.org/userfiles/file/1\\_2Encountercollectionindividuals.pdf](http://www.patientprovidercommunication.org/userfiles/file/1_2Encountercollectionindividuals.pdf)

### **The Central Coast Children's Foundation Medical Encounter Communication Board**



Communication during a medical encounter can often be imperfect and complicated for everybody, but for patients who for various reasons are *communication vulnerable* (speak a foreign language, have pre-existing medical conditions that limit communication capabilities) this can be an extremely scary situation.

To help support patient:provider communication during these often difficult interactions, the Central Coast Children's Foundation has developed a free downloadable communication sheet designed for regular medical encounters in clinics or doctors' offices, and during emergency room visits. On one side are general phases and statements one might use in a medical office. On the other side are questions and statements that one might need in conversing directly with a nurse or doctor.

[http://www.patientprovidercommunication.org/userfiles/file/1\\_1MedicalEncounterCommunicationBoard.pdf](http://www.patientprovidercommunication.org/userfiles/file/1_1MedicalEncounterCommunicationBoard.pdf)

## **Web Sites**

### **Webinar Slides: Standards of Care for Adults with Intellectual and Developmental Disabilities, by Sarah Ailey, Diana Umali and Christine Uyen**

This presentation uses a case study of a patient with an intellectual and developmental disability (IDD). It demonstrates effective ways to communicate with patients with IDD, and the need for appropriate standards of care. It provides a detailed model for a nursing care plan to enhance communication for patients with IDD. The goal of the plan is that "the patient's communication skills will be assessed and maximized to facilitate nursing communication with the patient." It calls for ongoing assessment of the patient in four areas: 1) Receptive Communication, 2) Expressive Communication, 3) Use of Alternative Communication Methods and 4) Nonverbal Communication, and includes useful references.



Click here: [http://aadmd.org/sites/default/files/Sarah\\_Ailey\\_2-16-12\\_webinar-slides.pdf](http://aadmd.org/sites/default/files/Sarah_Ailey_2-16-12_webinar-slides.pdf)

### **NHS Education for Scotland: Communicating, Connecting, Caring**

"Good communication and effective, caring relationships are essential in a person-centered healthcare service. As a practitioner you need more than opportunities to simply acquire a set of communication skills, approaches or values. You need to be supported to continually improve and integrate desired communication behaviors into daily practice." This site offers tools and information and resources in four areas: 1) principles of good communication, 2) developing self, 3) developing others and 4) practitioner stories.



<http://www.nes.scot.nhs.uk/education-and-training/by-theme-initiative/communicating,-connecting,-caring.aspx>

### **Augmentative Communication Inc. Newsletter: Communication across the healthcare continuum**



Figure 3. Triage nurse with a communication board.<sup>14</sup>

Language, cultural, behavioral, and physical barriers can get in the way of a successful medical experience. Communication is key. This issue of an AAC newsletter outlines the challenges patients and providers face with communication in various medical situations. It gives information and resources to help meet these challenges.

[http://www.augcominc.com/newsletters/index.cfm/newsletter\\_129.pdf](http://www.augcominc.com/newsletters/index.cfm/newsletter_129.pdf)

### **Augmentative Communication Inc. Newsletter: Communication access for people who rely on AAC**

Everyone has a right to communicate, even if the way they do so is different. In this newsletter, you can read about the rights people with complex communication needs advocate for, and discusses the training and education available for those who want to help insure these rights.

[http://www.augcominc.com/newsletters/index.cfm/newsletter\\_49.pdf](http://www.augcominc.com/newsletters/index.cfm/newsletter_49.pdf)



### **Toddler Test or Procedure Preparation**

Toddler will probably cry regardless of test or procedure



Helping your young child prepare for a medical test or procedure can reduce anxiety, increase cooperation, and help the child develop coping skills. This article gives tips for how to prepare

before a procedure, what to expect during a procedure and how to best comfort your child.  
Read the full article at:

<http://www.nlm.nih.gov/medlineplus/ency/article/002056.htm>

### **Josie King Foundation**

Lack of preparation, understanding, and communication can lead to tragedy. The Josie King Foundation's website offers advice on how to protect your loved ones as well as links and resources that will prepare you for medical encounters. You can visit the website at:



**JOSIE KING FOUNDATION**  
*creating a culture of patient safety, together*

<http://www.josieking.org/Home>

### **Doctor's Visit Checklist**

This website shows data collected in response to the question: When you visit your doctor, do you...

- 1) Take a list of concerns?
- 2) Take your medication list or medicine bottles?
- 3) Ask questions until you understand everything?

It also has a list of resources such as tips for interaction with your doctor and logs to make sure you have everything covered.

[http://www.alz.org/alzheimers\\_disease\\_doctors\\_visit\\_checklist.asp](http://www.alz.org/alzheimers_disease_doctors_visit_checklist.asp)

When you visit your doctor, do you ...

		# of responses	%
1	Take a list of concerns?		
	Yes 	2579	54%
	No 	1460	36%
2	Take your medication list or medicine bottles?		
	Yes 	2212	55%
	No 	1827	45%
3	Ask questions until you understand everything?		
	Yes 	2651	66%
	No 	1388	34%

### **Equal Rights Center: Ill-Prepared: Health Care's Barriers for People with Disabilities**



With nearly three decades of experience as an advocate of the disability community, the Equal Rights Center (ERC) has been a sounding board for scores of individual complaints about inaccessible health care.

This report brings some of those complaints to light and documents studies that show how ill-prepared the health care system still is in accommodating persons with disabilities, *despite* existing legislation to insure equality.

Knowing what your rights are is an important first step in self-advocacy. The specific rights created by section 504 of the Rehabilitation Act are explained clearly in this report. It is a good resource for those who have questions about the current situation regarding accessibility to healthcare for people with disabilities.

The Equal Rights Center Website can be found at:

[http://www.equalrightscenter.org/site/PageServer?pagename=ERC\\_homepage](http://www.equalrightscenter.org/site/PageServer?pagename=ERC_homepage)

Below is a link to the report:

[http://www.equalrightscenter.org/site/DocServer/III\\_Prepared.pdf?docID=561](http://www.equalrightscenter.org/site/DocServer/III_Prepared.pdf?docID=561)

### **Scope About Disability**

A visit to the doctor can be a trying experience for any child. This website gives tips that have been contributed by other parents, care takers and professionals in order to make your visit go smoothly. If you don't see the answer to your question, it also has a forum on which to post questions and access to experts.



<https://community.scope.org.uk/tips/medical-appointments>

### **Why Culturally Competent Care?**

Today's multicultural climate requires health care workers to be more culturally aware, and to understand and practice cultural *humility*. This website provides resources to help health professionals provide the best service for patients from all backgrounds. There are videos, case studies, and other resources. The web site offers CME/CE credit, with the goal of providing health care professionals with the kinds of awareness, knowledge, and skills they need to better serve the increasingly diverse U.S. population. <https://cccm.thinkculturalhealth.hhs.gov/>



### **CONDITION HELP**



The Children's Hospital of Pittsburgh has a unique patient safety program, Condition Help, that seeks to improve communication between families and caregivers. If families of patients at the hospital feel their child's immediate health



may be endangered and/or their concerns are not being addressed, they can call a hotline to have their child evaluated by a different medical team. The medical team consists of a physician, nurse administrator and patient representative, who are available 24/7. After receiving a call, the team comes to the child's room within minutes. This project has empowered families, and has reduced errors. (For more information on results of the project, check out the News Release below.)

News Release: <http://www.chp.edu/CHP/061808>

Condition Help:

[http://www.chp.edu/cs/Satellite?c=eHA\\_Content\\_C&cid=1189459525424&pagename=CHP%2FeHA\\_Content\\_C%2FCHP%2FTemplate%2FCHP\\_Layout\\_04\\_Content\\_Page\\_Template](http://www.chp.edu/cs/Satellite?c=eHA_Content_C&cid=1189459525424&pagename=CHP%2FeHA_Content_C%2FCHP%2FTemplate%2FCHP_Layout_04_Content_Page_Template)

Children's Hospital of Pittsburgh: <http://www.chp.edu/CHP/Home>

### **My First Eye Test at the Hospital**

**Free PDF.** This downloadable four-page PDF leaflet is a simple step-by-step explanation of what will happen on a child's eye-clinic appointment. Developed by Widgit in the U.K., in association with Colchester Hospital University NHS Foundation Trust.

<http://www.widgit-health.com/downloads/my-first-eyetest.htm>



### **Patient Feedback**

It can be difficult for people who need communication supports to give feedback during medical encounters. This video from Scotland illustrates common communication problems in medical settings and describes how to make complaints and give feedback about services. Two men share their experiences. The video emphasizes the need to involve people with communication support needs *routinely* in providing feedback on the quality of their service delivery. Included are downloadable resources (e.g., a making a complaint leaflet) for overcoming communication barriers.

<http://www.nes.scot.nhs.uk/education-and-training/by-theme-initiative/communicating,-connecting,-caring/developing-others/reviewing-practice-and-giving-feedback/giving-feedback.aspx>

## Arthur Kleinman's Questions



Face to face communication time between doctors and patients is getting shorter and shorter. While most doctors realize the importance of understanding their patients' health beliefs and perspectives, they often have a difficult time gleaning these things during time-constrained consultations. Arthur Kleinman, a psychiatrist and anthropologist, has proposed that instead of simply asking patients, "Where does it hurt," physicians should focus on eliciting the patient's answers to "Why," "When," "How," and "What Next."

Patients may find it useful to be aware of these questions and perhaps try to address them when their medical practitioners do not choose to.

In the article cited below, Dr. Namratha Kandula explains how she uses Kleinman's questions to better understand her patients and how the questions are especially useful when interacting with patients who have complex communication needs.

<http://thehealthcareblog.com/blog/2013/06/11/the-patient-explanatory-model/>

Kleinman's 9 Questions Model can be found at:

<http://pilot.train.hrsa.gov/uhc/pdf/modules/03/Module03JobAidModelKleinman.pdf>

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## Videos

### *Vision Statements, NHS Education for Scotland*



These "Vision Statements" include 10 videos of individuals with communication disabilities sharing their personal experiences with communication in a variety of settings, and suggest what is most important to remember about communication. Each video includes links to further resources that can be used to improve communication. The 10 video topics

are: 1) Booking Appointments, Contacts and Attracting Attention, 2) Time, 3) Knowledge of

Communication Tools, 4) Communication Support and Health, 5) Information, 6) Staff Attitude, 7) Patient at the Centre, 8) Physical Environment, 9) Patient Feedback and 10) Signage.

<http://www.nes.scot.nhs.uk/education-and-training/by-discipline/allied-health-professions/resources,-publications-and-useful-links/making-communication-even-better/vision-statements.aspx>

### **Partner Assisted Auditory Scanning**

This video demonstrates a non-electronic communication technique for people with ALS and other conditions that make speech difficult because of limited movement. Partner assisted auditory scanning allows an individual to select letters of the alphabet without speaking or pointing, to spell words and to use common abbreviations.

Individuals only need to signal yes using whatever gesture is easiest for them, such as blinking or glancing in a certain direction. Partner assisted auditory scanning requires no physical materials--just two people using a simple chart. <http://www.youtube.com/watch?v=pLb6-Oi3uR0>.



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### **Disability Rights Stories**

The Disability Rights Education Defense Fund (DREDF) has produced *Healthcare Stories*. *Healthcare Stories* are downloadable videos, each interviewing a person with a variety of disabilities from around the United States. Interviewees speak candidly about their experiences accessing healthcare and describe specific “stories,” pointing out issues that interfere with quality healthcare.



The twelve videos last about 15 minutes each. DREDF plans to add more stories from people with developmental disabilities. Their goal is that *Healthcare Stories* help disability advocates, health advocates, and others launch discussion and actions that address persistent barriers to healthcare and suggest

important solutions that will improve healthcare for people with disabilities.

<http://www.dredf.org/healthcare-stories/>

### **Crossing Cultures**

*Crossing Cultures* features healthcare providers and immigrant patients from Ethiopia, Sudan, Cambodia, Laos and Russia, who demonstrate how to apply a simple model known as "LEARN" to any cross-cultural encounter. LEARN is an acronym that makes it easy to remember five vitally important things concepts: Listen, Explain, Acknowledge, Recommend, and Negotiate.



*Crossing Cultures* was developed as a training video for health care providers and is easily incorporated into discussions about culturally competent care, healthcare disparities, language access, patient safety and more. The video is available for purchase (\$25.10 plus shipping and handling). You can also borrow the video. The *Crossing Cultures* website contains a sample agenda and handout to help you plan a 60-minute workshop incorporating the video. Purchase video: <https://wwwcreatespace.com/323567>.

Borrow video: <http://www.health.state.mn.us/divs/idepc/refugee/library/order.html>

### **National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care**

The United States Department of Health and Human Services (HHS) has released enhanced National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care – a blueprint to help organizations improve health care quality in serving the nation's diverse communities. The enhanced National CLAS standards are grounded in a broad



definition of culture – one in which health is recognized as being influenced by factors ranging from race and ethnicity to language, spirituality, disability status, sexual orientation, gender identity, and geography. The standards provide a framework to health and health care organizations for the delivery of culturally respectful and linguistically

responsive care and services.

[https://www.thinkculturalhealth.hhs.gov/Content/clas.asp#clas\\_standards](https://www.thinkculturalhealth.hhs.gov/Content/clas.asp#clas_standards)

You can access the HHS *Blueprint*, which provides extensive explanations of each *National CLAS Standard*, including implementation strategies at:

[https://www.thinkculturalhealth.hhs.gov/GUIs/GUI\\_TCHRegister.asp?mode=new&clas=yes](https://www.thinkculturalhealth.hhs.gov/GUIs/GUI_TCHRegister.asp?mode=new&clas=yes)

or their fact sheet at:

<https://www.thinkculturalhealth.hhs.gov/pdfs/NationalCLASStandardsFactSheet.pdf>

You can also access a video (■Think–Speak–Act Cultural Health) on the importance of culturally competent care at:

<https://www.thinkculturalhealth.hhs.gov/FlashPlayer/play508.asp?Video=QHpart1>

***Your Community in Dialogue: Nursing Homes/Elderly Care Facilities – Will Your Loved Ones Be Adequately Cared For During a Disaster or Emergency?***



The degree of neglect and abuse which has been reported in far too many nursing homes is deeply troubling. Neglected, abused, and threatened, nursing home residents can suffer physically and emotionally. Painful bedsores, broken bones, or even premature death can result from neglectful and outright abusive treatment. Unfortunately, a serious lack of emergency preparedness in these nursing

home facilities may just be one more offense to add to the list. Watch the video at:

[http://www.ice-pack.com/EP\\_news/2012/05/your-community-in-dialogue-nursing-homeselderly-care-facilities-will-your-loved-ones-be-adequately-cared-for-during-a-disaster-or-emergency/](http://www.ice-pack.com/EP_news/2012/05/your-community-in-dialogue-nursing-homeselderly-care-facilities-will-your-loved-ones-be-adequately-cared-for-during-a-disaster-or-emergency/)

***NexTalk for Deaf and Hard of Hearing Patients***

Baton Rouge General Hospital has employed an exciting resource for its deaf and hard of hearing patients called NexTalk. NexTalk takes the form of a mobile video conferencing unit that enables off site interpreters to provide interpretation services at anytime. The units also allow patients to communicate with friends and family through video conferencing during their hospitalization. To learn more click the below link:



[http://www.youtube.com/watch?v=U0bjx01GEAM&feature=youtube\\_gdata\\_player](http://www.youtube.com/watch?v=U0bjx01GEAM&feature=youtube_gdata_player)

***Serving People Who are Deaf in Hospitals***





The experience of deaf and hard of hearing individuals in a hospital setting is often confusing and frightening. Without the ability to communicate, a patient can be left in the dark regarding his or her own care. This need not be the case. With proper communication services, the hospital experience can be positive instead of terrifying.

[http://www.youtube.com/watch?v=N2pwdKqSV7c&feature=youtube\\_gdata\\_player](http://www.youtube.com/watch?v=N2pwdKqSV7c&feature=youtube_gdata_player)

### **Assisting in Preparing for a Doctor's Visit and Communicating with a Physician**



The average amount of time a patient will spend talking with their physician is a grand total of seven minutes. With such a short time, preparation is vital. Preparing a written agenda, a list of things you want to discuss, or sending questions to your doctor in advance are all good ways to prepare. Communication is the key to taking control of your own care. The following video provides information about an organization called

Health Assist that can help you to get prepared and coordinate your medical information with your past and present physician.

[https://www.youtube.com/watch?v=QmRJ35ogCds&feature=youtube\\_gdata\\_player](https://www.youtube.com/watch?v=QmRJ35ogCds&feature=youtube_gdata_player)

## **Smartphone and Tablet Communication Apps**

**SmallTalk Pain Scale** (<http://itunes.apple.com/us/app/smalltalk-pain-scale/id403058256?mt=8>)

- **What is it?** This app contains a series of images and pain descriptions that let the user communicate the type and level of pain. It is designed for people with aphasia, apraxia and dysarthria.
- **How much is it?** Free
- **Platforms:** iPhone, iPod Touch, iPad. Requires iOS 7.0 or later.
- **Reviews:** Some reviews mentioned that this app does not allow for sentence construction, or any editing. However, it does allow for a great deal of specificity by offering vocabulary for "body parts, positional words, and pain-related adjectives (dull, sharp, aching, radiating, etc.)."



**Verbally** (<http://itunes.apple.com/us/app/verbally/id418671377?mt=8#>)

- What is it? A text-to-speech app intended especially for people with AAC needs. Users type the phrase that they wish to convey, and *Verbally* speaks it. The app allows users to choose from several male and female voices and three different keyboard layouts. For ease of use, the app has a word predictor and two core grids – one for words and one for phrases. There is no need for an internet connection to use it, either.



- How much is it? Free
- Platforms: iPad. Requires iOS 4.0 or later.
- Reviews: Verbally has received good reviews. Though the voices could be improved, the app's "purpose and functionality make it so valuable."

**My Talking Phone** (<http://itunes.apple.com/us/app/my-talking-phone-free-text/id385793450?mt=8>)

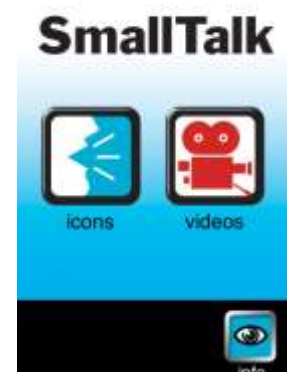
- What is it? A text-to-speech app that lets the user type and talk with the device's keyboard. Users can adjust the pitch and speed of the voice.
- How much is it? Free
- Platforms: iPhone, iPod Touch, iPad. Requires iOS 3.0 or later.
- Reviews: Users find My Talking Phone "simple" to use; however, several reviewers commented that the app had a lot of ads.



**SmallTalk Aphasia : Female** (<https://itunes.apple.com/us/app/smalltalk-aphasia-female/id310102858?mt=8> )

**Male:** (<https://itunes.apple.com/us/app/smalltalk-aphasia-male/id403064267?mt=8> )

- What is it? This app contains phrases and images to help people who have difficulty speaking. Users select the word or phrase, then let the app "speak." The categories include doctor's appointments and emergencies. Users can personalize the vocabulary as well. There is also a mouth-





positioning feature that helps the user practice speaking at his or her own pace.

- How much is it? Free
- Platforms: iPhone, iPod Touch, iPad. Requires iOS 7.0 or later.
- Reviews: Users call this app “a real find for folks with communication challenges.” Although the vocabulary is “limited,” and there is no gender option, reviewers agree that the app is easy to use and facilitates communication for those with special needs.

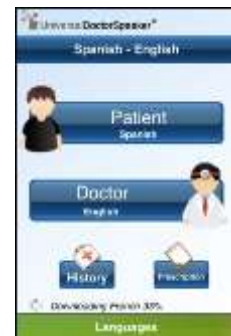
**Talk Assist** (<http://itunes.apple.com/us/app/talk-assist/id329338159?mt=8#>)

- What is it? A text-to-speech app that allows users to “speak” by typing a message and then having it read aloud. The phrases may be saved, and a bookmark feature lets users store favorite phrases for frequent use.
- How much is it? Free
- Platforms: iPhone, iPod Touch, iPad. Requires iOS 3.0 or later.
- Reviews: Reviews say that Talk Assist has a “simple” interface and is overall a good app. However, users would like to see an option for a female voice. Another user wrote that Speak It (which costs \$1.99, see below) is a better app despite the slightly higher cost.



**Universal Doctor Speaker** (<http://itunes.apple.com/us/app/universal-doctor-speaker-full/id389202856?mt=8#>)

- What is it? This app is designed to help doctors communicate with patients who speak a different language. There are six language options (Chinese, English, French, German, Portuguese and Spanish) with more than 500 words and phrases for each. The app includes translations for sharing general medical information, accidents and common illnesses. There are two settings, one for the patient and one for the health care professional.
- How much is it? \$5.99
- Platforms: iPhone, iPod Touch, iPad. Requires iOS 6.0 or later.
- Reviews: One user calls this app “a must have” that can be used for travel as well as in emergencies.



**Speak it! Text to Speech** (<http://itunes.apple.com/us/app/speak-it-text-to-speech/id308629295?mt=8#>)



- What is it? A text-to-speech app that allows users to copy articles, emails, PDFs and other documents to be read back to them. Users can also type their own text and hear it spoken. *Speak it!* lets users send audio files, save phrases and choose from a choice of voices (other language versions, including French and Spanish may be purchased for an extra \$0.99).
- How much is it? \$1.99
- Platforms: Android, iPhone, iPod Touch, iPad. Requires iOS 4.3 or later.
- Reviews: The Muscular Dystrophy Association has called *Speak it!* “useful” for people with disabilities. Other user feedback is overwhelmingly positive, with one reviewer calling its voice quality “on par” with Kindle. Some expressed difficulty copying and pasting a large amount of text, but were pleased with the app’s overall quality.

#### **Healthcare Communication App** (<http://appcrawlr.com/android/healthcare-communication-app> )

- What is it? The Healthcare Communication App (HCA) uses text-to-speech technology and artfully-drawn picture icons. The patient taps an icon indicating a want or a need and HCA speaks it for them.
- How much is it? \$49.00
- Platforms: iPad, Android
- Reviews: Reviews say that, “healthcare communication app enhances communication between patients and caregivers.”



#### **In Case of Emergency (ICE)** (<http://appcrawlr.com/android/emergency-ice-free> )

- What is it? This app helps you in case of emergency. The first responder is able to get information about the person she/he is dealing with and find out whom to call with only a few clicks. As part of your mobile health management, it stores important information that in case of an emergency.
- How much is it? Free
- Platforms: Android
- Reviews: Reviews say that, “all data can be entered and displayed separately for each family member.” “Gives me a great peace of mind in the event of an emergency.”



#### **MediBabble Translator** (<http://medibabble.com/press.html> )

- What is it? MediBabble is a free, professional-grade medical translation tool. Its high quality translation, helps doctors and patients communicate across language barriers.



- How much is it? Free
- Platforms: Compatible with iPhone, iPad, and iPod touch. Requires iOS 5.1 or later.
- Reviews: "One problem - when searching for a term, if you want to search multiple times, the app stops working after the first search. I need to close the app completely to do another search. Otherwise I'm loving this app. I love this app because it is well organized and has both verbal and written interpretations/translations."

**MyDirectives** (<https://itunes.apple.com/us/app/mydirectives-mobile/id931433126?mt=8&ign-mpt=uo%3D4> )

- What is it? *MyDirectives* is a tool that will help you organize all of your medical information and preferences. It makes it easy to create a state-of-the-art emergency medical directive. You can answer questions in your own words or pick from a selection of the most common answers. Add your thoughts with as much detail as you wish. You can even add your own video responses.
- How much is it? Free
- Platforms: Compatible with iPhone, iPad, and iPod touch. Requires iOS 7.0 or later.
- Reviews: "This service is, incredibly, free, legal and accessible every minute of every day anywhere in the world! Yes it's a particularly delicate subject, but best to sort these things out in your own time than stuck in A&E, intensive care or leaving it to family to decide if you are unable to communicate. It allows those placed in charge of your care to understand your wishes and desires in a health crisis. They have set questions with quite straightforward options/answers to select, but also free text boxes that you can add in anything specific to you which in the current climate of individuality seems like a sensible idea."



**Manage My Pain Lite** (<https://play.google.com/store/apps/details?id=com.lcs.mmp.lite> )

- What is it? *Manage My Pain* helps you and others better understand what you are going through. It has helped thousands of people with conditions like fibromyalgia, migraines, arthritis, or back pain better understand their symptoms and provide evidence of their pain for their doctors, insurance companies, or government agencies. *Manage My Pain* creates reports designed by doctors for doctors - ones that your doctor will actually read.



- How much is it? Free
- Platforms: Android, 2.3 and up.
- Reviews: "Loved it. It was easier to convey my pain to my doctors with this tracking app."

I'm also able to see what causes me more pain.” “Not bad for free. May have to buy it to see if paid is worth it but so far its pretty good. Time thing is a bit screwy other then that only thing it needs is better set up help”

**Health Mapper - the app for monitoring ANY long-term health condition.**

(<https://itunes.apple.com/us/app/health-mapper-app-for-monitoring/id914881814?ls=1&mt=8> )

**[?] What is it?** Use Health Mapper to quickly and easily monitor your health condition(s). Track symptoms, medication, measurements and anything else that's important to your health like exercise, diet, sleep and stress.

- **How much is it?** Free
- **Platforms:** Compatible with iPhone, iPad, and iPod touch. Requires iOS 6.0 or later.
- **Reviews:** “Easily the best app I’ve found for tracking my health conditions. I have a couple of health conditions that I keep track of and this app really helps show the doctor how things are going. Strongly recommend.”



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## **Annotated Bibliography**

**1. University of Washington. (2012). Getting the Most Out of Health Care Visits [Factsheet]. Multiple Sclerosis Rehabilitation Research and Training Center.**

<http://msrrtc.washington.edu/>.

Getting the most out of your health care visit will improve your confidence and your health. This article outlines the “PACT” method (Prepare, Ask Questions, Create a Plan, and Take-Away Materials) to help you take an active role in your health care and communicate successfully with your doctor. Here you can find what to expect during a health care visit, tips on how to prepare, and additional resources.

**2. Cortes, Dharma E., Norah Mulvaney-Day, Lisa Fortuna, Sarah Reinfeld, and Margarita Alegria. (2009). “Patient-Provider Communication: Understanding the Role of Patient Activation for Latinos in Mental Health Treatment,” *Health Educational Behavior*, 36: 138-154. Available at: <http://heb.sagepub.com/content/36/1/138>**

Patients can take a more proactive role in decisions about their health care by asking questions about their treatment options. Yet, asking the right questions is more successful when patients know how to formulate questions and to get the information that they need. Many patients do not have these skills, but could acquire them through education and training. **The Right**

### **Question Project-Mental Health (RQP-MH)**

**approach devised a model for training these skills, working with a mostly-Hispanic population.**

Participants underwent training, held interviews to gauge how they incorporated the information. The researchers noted that the participants were more inclined to ask questions about their care than before. While more research needs to be done over a longer period of time, this method suggests one way in which patients could be trained to take a more active role in decision-making.



3. Zoffmann, Viebeke, Ingedgerd Harder, and Marit Kirkevold. (2008, January). "A Person-Centered Communication and Reflection Model: Sharing Decision-Making in Chronic Care," *Quality Health Research*, 18: 670. Available at: <http://qhr.sagepub.com/content/18/5/670>

Shared-decision making (SDM) empowers patients to take part in decisions about their own health care; however, in practice, SDM is underused. It is typically the health care provider who



"Don't think of me as a Proctologist.  
Think of me as Colon Tech Support."

informs the patient about health needs, instead of the other way around. A group of Danish researchers studied SDM among diabetes patients and their doctors and developed a **model of person-centered communication**. The model encourages a disease-management approach, rather than a strict focus only on the disease's effects, as well as a more individualistic look at the patient's circumstances instead of generalization. Implementation can be difficult, but it helps the patient take a proactive role in his or her own health care.

4. Ngo-Metzger, Quyen, Gillian R. Hayes, Yunan Chen, Ralph Cygan and Craig F. Garfield. (2010). "Improving Communication between Patients and Providers Using Health Information Technology and Other Quality Improvement Strategies: Focus on Low-Income Children," *Medical Care Research and Review*, 67: 246S-267S. Available at: [http://mcr.sagepub.com/content/67/5\\_suppl/246S](http://mcr.sagepub.com/content/67/5_suppl/246S)

Patient-provider communication in the pediatric field is often overlooked, but it is a significant factor in the success of treatment. Studies have shown a gap between the children and family's expectation of health care and what doctors actually provide. Low-income children are especially at risk; their families are statistically less health literate and more prone to health risks. This study examined the use of information technology to help bridge the gap – using email, the telephone, and even video games as a way to inform young patients about their conditions and to follow up with them. **The study suggested that information technology can help children learn about health care and be better-suited to receive quality treatment.**



5. Beukelman, David, Susan Fager, and Amy Nordness. (2011). "Communication Support for People with ALS," *Neurology Research International*, 2011. Available at: <http://www.hindawi.com/journals/nri/2011/714693/>

People with amyotrophic lateral sclerosis (ALS) almost always suffer a motor speech disorder at some point during the disease's course. When this occurs, the ability to speak naturally rapidly decreases, and there is often little time to implement an effective augmentative and alternative communication (AAC) program. This article stresses the importance of early intervention and raises awareness of the long-term AAC support that can help people with ALS. AAC support takes many forms, from touch-screens to eye-tracking systems; patients with ALS typically use them until the end of their lives. Thus, **it is essential to accurately and quickly develop a support program suited for the patient's needs.**

6. Long, Andrew, Anne Hesketh, and Audrey Brown. (2009, May 29). "Communication Outcome after Stroke: A New Measure of the Carer's Perspective," *Clinical Rehabilitation*, 23: 846-856. Available at: <http://cre.sagepub.com/content/23/9/846>



Researchers have noted the psychological strains on the caregiver of a person who has suffered a stroke; little study has been done specifically on communication, however. Many people who have a stroke develop a communication problem, and the caregiver also must cope with the new communication challenges. To better understand these effects, researchers used the Carer Communication Outcome after Stroke (COAST) scale. The scale measured the level of communication after the stroke and how this affected the caregiver's quality of life. The results confirmed that communication barriers do affect caregivers, suggesting that **programs focusing on caregiver support should include communication as well as psychological needs.**



7. Hemsley, B., Kuek, M., Bastock, K., Scarinci, N., & Davidson, B. (2013). Parents and children with cerebral palsy discuss communication needs in hospital. *Developmental Neurorehabilitation*, 363-374. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/24228709>

The aim of this study was to understand the communication needs and experiences of parents and children with cerebral palsy (CP) and complex communication needs (CCN) in hospital. Focus groups with 10 parents and interviews with seven children with CP and CCN were analyzed for content themes. **Results demonstrated that children often want to communicate directly with hospital staff to: gain attention, answer yes/no, convey basic physical needs, give and receive information, control their environment and participate in preferred activities.** Barriers to communication included lack of access to augmentative and alternative communication (AAC), staff preferring to communicate with parents and lack of time to communicate. Results highlight strategies for successful communication, **the role of the parents in supporting communication** and provision of AAC systems for children in hospital. Policy and practice implications in the preparation of children with CP and CCN for communication in hospital are discussed.

8. Morris, M., Dudgeon, B., & Yorkston, K. (n.d.). A qualitative study of adult AAC users' experiences communicating with medical providers. *Disability and Rehabilitation: Assistive Technology*, 8(6), 2013, 472-481.

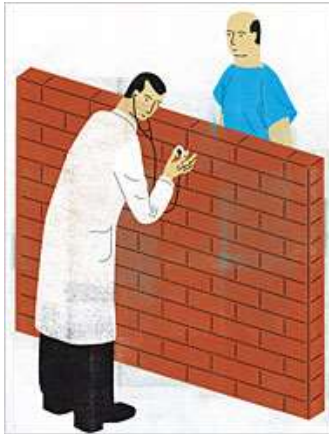
Patients with communication disabilities face multiple barriers to communicating with medical care providers. To explore these barriers, researchers conducted a series of face-to-face interviews and an online focus group with **participants who use augmentative and alternative communication systems and methods.** Participants described multiple frustrations in communicating with medical care providers. Themes that arose included: planning and



preparing for the appointment, time barriers, inappropriate assumptions, relationship building and establishing rapport, medical decision making and implementing the plan.

9. Rayner, H., & Marshall, J. (2003). Training volunteers as conversation partners for people with aphasia. *International Journal of Language & Communication Disorders*, 38(2), 149-164.

One of the most disabling consequences of aphasia is the way it excludes the person from conversation. Exclusion can lead to confusion and misunderstanding during medical encounters. This study evaluated the possible solution of **training the conversational partners of aphasic people**. Questionnaires given before and after the training documented significant improvements in the scores of conversational partners. There were comparable gains in the participation of the aphasic subjects, which again occurred after training. The study demonstrates that a short training course can change the knowledge and practice of experienced conversational partners. This can lead to a better health care experience for those with aphasia.



10. Gillette, Y. (2012). *Achieving Communication Competence Three Steps to Effective Intervention*. Verona, Wisconsin: Attainment Company.

A trip to the doctor's office can be a frightening experience for anyone. Add the additional frustrations of having to use an alternative means of communication and the situation can seem impossible. You know how difficult interaction can be. You may ask yourself, "What can I do? Can a device help? Can others help? Where do I begin?" This PDF provides answers to these hard questions and can get you started on your way to communicating more competently in any situation, including medical encounters

[http://www.attainmentcompany.com/sites/default/files/pdf/sample/ACC\\_Sample.pdf](http://www.attainmentcompany.com/sites/default/files/pdf/sample/ACC_Sample.pdf)

12. Groopman, J. (2007). *How doctors think*. Boston: Houghton Mifflin.



Miscommunication leads to misdiagnosis. Jerome Groopman **addresses how doctors need patients to be fully engaged and asking questions**. This book focuses on one aspect of the doctor-patient interaction: how it influences a physician's diagnosis, and even his ability to make a diagnosis. **It gives positive and negative examples and will help patients avoid the same mistakes that they make when they assume the doctor knows what they are**

**talking about.** (Check out Michael Crichton's review of this book @ [http://www.nytimes.com/2007/04/01/books/review/Crichton.t.html?pagewanted=1&n=Top/Fatures/Books/Book Reviews&\\_r=0](http://www.nytimes.com/2007/04/01/books/review/Crichton.t.html?pagewanted=1&n=Top/Fatures/Books/Book%20Reviews&_r=0))

13. Wyatt, M. (2015, February 17). 5 Things Most Doctors Get Wrong. Retrieved February 20, 2015, from [http://www.huffingtonpost.com/karen-m-wyatt-md/5-things-most-doctors-get-wrong\\_b\\_6655978.html](http://www.huffingtonpost.com/karen-m-wyatt-md/5-things-most-doctors-get-wrong_b_6655978.html)

It's important for patients to get insight into how doctors think in preparation for medical encounters. This article, by a doctor about her experience with other doctors, describes five things that most doctors get wrong.

1. They don't listen.
2. They don't establish a relationship with the patient.
3. They don't treat the patient as a whole person.
4. They don't discuss end-of-life issues in a timely manner.
5. They choose fear over wisdom.

To read the full article please click : [http://www.huffingtonpost.com/karen-m-wyatt-md/5-things-most-doctors-get-wrong\\_b\\_6655978.html](http://www.huffingtonpost.com/karen-m-wyatt-md/5-things-most-doctors-get-wrong_b_6655978.html)



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Topics addressed include:

A. Why is preparing for medical encounters so important?

B. What kinds of communication barriers can patients anticipate across various healthcare settings (clinic vs. doctor's office, emergency room vs. ICU, etc.)

- High-stake contexts? (ER, ICU, discharge, disaster situations, etc.)
- Acute care (bedside, intake, discharge, surgery, etc.)
- Rehab, Skilled Nursing Facilities
- Long-term care facilities/hospice/home health

C. What communication breakdowns commonly occur? What preparations can prevent them?

D. What tools and materials can professionals outside health care systems use to prepare their clients and client's family members.

- Health Communication Passports: inform medical practitioners of vital health information. Clients keep on their person.
- Hospital Discharge Checklists: ensure a patient's discharge plan from the hospital is comprehensive, complete, and understood by patients
- Apps for smartphones and tablets: help retain vital medical information, stay organized, keep permanent medical record, share their notes with doctors/etc. via email, address key questions during medical encounters, "speak" for non-verbal patients, record vital medical information, etc.
- Videos, YouTube references and guides: for families and individuals with disabilities to get information about accessible, appropriate care in compliance with U.S. disability law;

- References to websites: how to connect communication vulnerable clients to available, free downloadable resources aimed at preventing catastrophic communication breakdowns during future medical encounters.