Chapter

5

THE BUILDING BLOCKS FOR TELEHEALTHCARE PROGRAM DESIGN

Many types of products and services can be used to build telehealthcare programs and to extend more occasional services to at-home patients. We begin this chapter by looking at new tools to extend the old: for instance, add-on devices to telephones to enhance sound and to television sets to enlarge pictures. Later in the chapter, we discuss programmable devices, including add-on items like alarm bells/lights connected to household clocks that can signal medication routine needs. These "extenders" can be used to work with the ordinary tools that are already very familiar to This Generation of home care patients.[1]

From an overview of these familiar items, we tread into the rapidly developing world of newer-tech, consumer products that can be multi-functional, including uses for healthcare. This range encompasses programmable devices such as hand-held personal digital assistants (PDAs). At first glance, you may not think that a familiar telephone or even the latest tech, in-color PDA can "do" anything that is healthcare related. This is a challenge for you: to review the products identified in this chapter and consider particular patients and their needs (the deaf cancer patient, the sometimes forgetful diabetic) and how they might be assisted via these new or different products.

The division between a healthcare product and a consumer product will often seem blurred and in fact indistinguishable. Generic tools, such as digital cameras, can be used periodically for tracking progress in wound healing; or for taking pictures for the family album of adorable grandchildren and remarkable pets. Obviously, these are multifunctional products, healthcare or otherwise. This appears to be a positive trend. Similarly, an accelerating consumer design trend is moving toward making all products and devices (healthcare or otherwise) manageable. Take, for instance, easy-to-turn doorknobs, easy-to-manipulate water faucets, and numerous other examples of what is referred to as "universal design." This trend is also a good thing for the ordinary aging

consumer whose ranks are growing. However, it is misleading to think that simply placing consumer-oriented products and devices in the home will improve home care patients' self-care routines. Providers need to do a great deal of planning for these products to be effective for their patients. To help you begin this effort, this chapter features the products, or the building blocks, needed for successful telehealth programs.

TOOLS FOR EXTENDING TELEHEALTHCARE SERVICES TODAY

Challenge: Matching tools with patients' needs

Key to successful use of telehealthcare, as any number of programs and case studies are beginning to demonstrate, is matching the device or resource appropriately with specific patients' needs and abilities. Identifying the appropriate instances for which providers could/should use more telecommunications-ready devices in the home to send more information to the patient and to send more patient information from the home is a challenge. What will help providers in this process is to narrow the choices to those tools and resources most appropriate for a particular chronic disease patient group—the most needy of persons living at home.[2]

In this chapter, we will focus on the following types of tools, with a particular focus on devices that can be used to extend their use as:

Low- and high- and somewhere in between-tech tools

- Telephones
- Television Sets
- Teaching Tools, such as CD ROMs and Videos
- Computers (with a focus on assistive devices and targeted software and Web Sites)
- Programmable Devices, such as Personal Emergency Response Systems (PERS) and Personal Digital Assistants (PDAs)
- Clinical Instruments, including peripheral devices and workstations

Chronic disease patients, who routinely require the highest number of services, may benefit from using more than one of these tools. In the final

segment of this chapter, examples that can be used for packaging a range of these tools and particular resources for care of pediatric asthma patients will be discussed. Potential "building blocks" have been assembled for your review.

THE TELEPHONE…AGAIN

Telephones are certainly not the highest-tech item of interest. But the household telephone can nevertheless play a significant role in assisting in patients' care and self management routines. For planning efforts, its very ordinariness makes it extraordinarily useful—the phone is extremely accessible and most patients already know how to use it.

It's ubiquitous, it's in nearly every home in the United States. Why not use it?

The following is a sampling of devices and services that can enable patients with particular needs to use the telephone effectively.

Telephone extenders

⇒ For those with difficulty :

HEARING

Treadline II Amplified Phone, Sound Resource, Inc. 847-323-7970	Amplified telephone with built-in control wheel that can increase sound by 15 decibels. Lighted push-button handset. Plugs into any modular wall phone jack, includes 6-foot cord.

SEEING OR WHO ARE BLIND

Unidialer, Task, Inc., 905-686-4129/ 800-463-5685	Single switch dials the phone; up to 30 phone numbers can be stored in memory. Can also be used to access a television and can perform up to 4 on/off functions for household appliances.

Telephone extenders continue on next page……

⇒ For those with difficulty:

HOLDING THE RECEIVER/DIALING/PUSHING TOUCH-TONE BUTTONS

Able-Phone (various models), Able-Phone, 619-668-0047 (www.ablephone.com)	Cordless phone with headset receiver which contains earpiece and microphone. User can place, receive, and terminate calls from the remote radio-wave-based unit (up to 750 feet away) by whistling into the microphone. Keypad allows control of phone by persons who use mouthsticks.

See also the Eye Gaze Computer System, under Computer Assisters, p. 67.

As indicated in each of these examples, relatively easy-to-use enhancements can enable use of the familiar household telephone by the home care patient.

THE HOUSEHOLD TELEVISION SET

Nearly as ubiquitous and accessible as the ordinary household telephone, the household television set (99% of all American homes have at least one tv), can also be used for healthcare purposes. For example, patients can watch cable television programs on particular healthcare topics, and caregivers can conduct more personalized "visits" via cable networking and television set-top cameras.

Television extenders

The following is a small sampling of devices and services that can enable home care patients with particular needs to extend the television set's use.

⇒ For those with difficulty:

HEARING

Wireless InfraRed TV Listening System, Four Point Design, 203-259-1174	Infrared amplification system for television. Transmitter is placed on top of television set and is plugged into an AC outlet.

SEEING OR WHO ARE BLIND

Freelance Homework, Overseer Low Vision Aids, 612-866-7606	Video magnifying system can be connected to any standard television set. For reading materials: magnification can be 6:1 and displayed on home television set screen.

These assistive devices make it possible for an available, older "tool"—the television set—to fit the needs of individual patients.

TEACHING TOOLS, SUCH AS SOFTWARE, CD ROMS, AND VIDEOTAPES

CD ROM TEACHING TOOLS. A wide range of electronically formatted educational materials are available for home care use. For example, menu planners have been designed to assist patients with daily meal planning. These planners help persons who live with particular conditions and who need to follow certain dietary restrictions and choose only certain foods. They automatically track how well the patients' food choices follow the daily guidelines that have been programmed for them in the electronic planner (for example: 2000 calories, 20 grams of fat, and so on). Patients make these food choices with the help of a device that, via tracking and analyzing mechanisms, helps them "know what to do."

⇒ Menu planners for patients with chronic disease:

The following is a very brief sampling of choices commercially available on software and CD-ROM.

- **HEART CONDITIONS**:

♦ NutriGenie American Heart Diet for Windows

Software provides tools for lowering cholesterol and avoiding obesity; it makes suggestions after it has calculated your ideal weight on daily caloric and nutrients amounts, according to your activity level.

(Sports/Science, Inc., 800-322-0688/www.nutri-guide.com)

♦ Dine Healthy for Windows

Software analysis of 10,000 foods for 27 nutrients, includes a patented "DINE Score" to measure how well you're doing in keeping with a specified regime. Lists more than 400 sports activities and exercises, with recipes and exercise analyses.

(Dine Systems, 800-688-1918/www.dinesystems.com)

- **DIABETES**:

♦ Healthview, on CD-ROM and software

Features thousands of foods with details on nutrients and exchanges, and prints reports that let you see daily interaction of food, blood sugars, medications, insulin, and exercise.

(Available from the Diabetes Mall, www.diabetesnet.com/hlthview.html)

and for children with diabetes:

♦ Cook'n for Diabetes series from DVO Enterprises has a juvenile diabetes version on CD titled: "The Kids, Food & Diabetes Family Cookbook," by Gloria Loring, of the Juvenile Diabetes Foundation International. Recipes for diabetic diets that kids can cook; special menus for theme parties, plus kitchen games (while things are cooking) like, tracking down the thief who stole Grandma's recipes.

(DVO Enterprises: 801-492-1290/ www.dvo.com/cookndiabetic.html)

VIDEOTAPES AS TEACHING TOOLS. Videotapes are an even more widely available teaching option for home use. They can assist patients with every facet of their care routines. For effective diabetic self care, for example, videos can present visual instruction for measuring insulin and demonstrate directives for rotating injection sites. Annual sourcebooks list thousands of healthcare-related audio-visual materials, many of them directed toward chronic disease patient needs. In fact, the amount of products to choose from can be as overwhelming as the growing number of healthcare-related Web sites that are available for both the professional and the consumer audiences.

All of this background information should answer the question: Do we need to make our own videotapes for hard to manage patients? Probably not. In addition to the enormous range of commercial video products, nearly every disease-related organization (such as the American Diabetic Association, the American Heart Association, the National Multiple Sclerosis Society, among numerous others) has its own extensive library of resources available for order. Identifying specific tapes often requires a simple phone call to these organizations or a trip to a library for review of sourcebooks. We do not endorse any tape or company as "better" than any other. Instead, we offer the following guidelines to help you in your selection process.

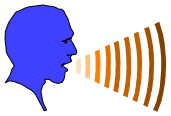
After you identify the sources and titles of the products, you need to take, additional steps in the review process to make the right choice and to eventually use the video materials effectively. All of these steps focus on whether the available tools—the videotapes—will "work" for the patient.

Videos that Work

You need to assess:

- Is the information current? Dated videos showing diabetics in leisure suits or bubble hair do's are distracting—even if the information is accurate. Look at the dates on the cassettes and, when viewing the tapes, screen for up-to-date actors using currently available products.

- Is the language readily understandable? Are stick figures or cartoons presented using language in captions that is almost childlike and overly simplistic?
Or, at the other end of the spectrum



- Are talking heads providing jargon (for the average patient) like: "To improve glycemic control and diminish cardiovascular risk factors, an exercise program should include aerobic exercise at 50-70% of an individual's O2 uptake…"

Put these materials back in the box and look for others that use language and care scenarios that the average patient can relate to.

Telecaring: One important step

This sifting and filtering of information is a big step toward customizing patient-care information. It helps you to make sure that the information is targeted and easy to use, so that it *will actually be used.*

The videos are not a substitute for nursing visits. Rather, they can provide valuable reiteration of instructions and information that had been provided by nurses or other clinicians. By hearing and seeing this information repeated via the videotapes, patients will be better able to know "what to do."

COMPUTERS (WITH A FOCUS ON ASSISTIVE DEVICES AND TARGETED SOFTWARE AND WEB SITES)

Computers in home health, routinely: Maybe not today, but soon

When assessing the regular and effective use of computers in home care, results are varied. According to recent surveys, at least half of all U.S. households have a personal computer. However, some home healthcare service providers may estimate that children, teenagers, or young adults reside in most of these households. That is, it's not the typical elderly and frail home health patient who is surfing the Net. Nevertheless, as more technology-comfortable baby boomers age, many home healthcare providers expect that delivering and extending services via personal computer will become a commonplace function. To hasten this trend, a rapidly growing range of products is becoming available.

COMPUTERS AND ASSISTIVE DEVICES. Patients who own and already feel (or could, with help, be made to feel) comfortable using computers may also need assistance with physical use of the keyboard and other components. Products which assist users by providing screen enhancements and other features are identified below. These products focus on making communications through the computer possible—some products assist patients in sending information; others help them to receive it in enhanced versions.

⇒ For those with difficulty:

WRITING

Dragon Systems (range of speech recognition programs) 800-843-7077	Speech recognition and voice input computer software to be used with author's dictated texts.

SEEING OR WHO ARE BLIND

Write Outloud Don Johnston, Inc. 800-999-4660	Voice input word processing program for persons with low vision or cognition disabilities. User can select voice and adjust volume and speed.

CONTROLLING MOTOR ABILITIES

Eyegaze Computer System LC Technologies 800-393-4293	A cursor control infrared interface for computers that is controlled via the user's eyes. Computer interprets where the eye is focused on the screen. (Other options permit the user to turn on lights and appliances and to dial a telephone by focusing his or her eyes at one of these choices.)

TARGETED SOFTWARE PACKAGES AND WEB SITES. Some at-home, computer-confident patients may also benefit from using targeted software packages and Web sites in their self management routines. No shortage exists of healthcare information packaged in software format and online sites on which the software can be stored and worked with (via making graphs of collected glucose data, for instance).

Self-help diabetes tracking software, for example, can help with keeping personal diaries for traveling, reminders, and various daily or occasional needs. The authorship of these software packages varies. Sometimes the authors can be diabetic patients who are also skilled in programming, others can be attributed to diabetes-device manufacturers. See, for example, Diabetes Online (www.diabetesonline.com).

One approach to Internet surfing: disease-specific bytes/ telecaring

A fairly recent addition to the trend in targeting and packaging patient information are Web sites that pharmaceutical company sponsor. These sites offer materials ranging in scope from clinical and general information on multiple sclerosis to planned packages that will focus on osteoporosis and other chronic diseases and conditions. Just as telemedicine used to be seen as a "Doc-in-a-Box" solution, these new entries are aiming toward becoming a "Disease-Management-With-a- Computer-Keystroke" solution.

Healthcare-related as well as disease-specific Web sites will be abundant in the near future, without question. Current statistics on growth may indicate 10, 100, even 1000 new sites per day (with varying degrees of comprehensive and accuracy)—any or all of these numbers sound believable. And of course this wealth of information can be completely overwhelming, as any first-time or long-time Internet user knows. However, caregivers—with some research and careful thought—can identify and narrow down what information from these Web sites will be relevant for their patients in their self management routines.

This is the next challenge:

We can think of the assistive devices that enable physical access as "physical enhancers" while tools for patient learning/practical use can be "information enhancers." Simply encouraging patients to use the Internet or even showing them how to do searches (for instance, a heart disease patient using the keyword "heart" can produce 14,000 unsorted "hits") is not really helpful. Targeting the information is a start; customizing it is the next step. As we noted in the CHESS program in Chapter 2 (see pages 23-24), staff presented customized information for the programs' HIV/AIDS population by marking easy-to-use computer keys.

Similar approaches are being used by the Detroit program for pediatric asthmatics (see pp.21-22) —the program provides easy and targeted Web access only to sites (or portions of sites) from the American Lung Association and other selected Internet locations.[3] Clinicians have decided on the best and most useful information for their particular patient population. When patients need answers to questions related to breathing, such as "What causes hiccups?" and "Why do certain things make me sneeze?" they can go to just a handful of respiratory issues-related sites for the answers or suggestions.

This approach works from the principle that people learn new information best from the familiar tools they've consulted in the past. Sorting and packaging ("bookmarking") the available and appropriate information in manageable quantities can create a personalized (electronic) sourcebook for patients, one that can provide focused answers and directives. This can be the patient's personal virtual bookshelf.

Easier said than done. How does a clinician begin to identify the "best" materials? So many Internet browsers now promise thousands of relatively unsorted "hits" (but, now, faster than before), that searching the Internet is like entering a conventional library where the books have no labels on the spine.

But this challenge has to be overcome. Clinicians' own experience and training should be the filtering mechanism for information that their patients need—not a 20-something software guru who surfed the Net and developed a slick "e-package"; not a neighbor who had "the same thing" as the patient and suggested a site for more information and a cure. Providers need to help their patients identify resources of value.[4]

Disease-specific Internet surfing

Among the best places to start searching, particularly for information needed by chronic disease patients, are Web sites designed by government-sponsored or national trade organizations. For example, investigating sites from the American Diabetes Association (www.diabetes.org), the Centers for Disease Control and Prevention (www.cdc.gov/diabetes), and the National Institute of Diabetes and Digestive and Kidney Disease of the National Institutes of Health (www.niddk.nih.gov), may be a very useful beginning for helping to direct diabetic patients toward the online world of helpful information. For heart disease patients, the American Heart Association (www.amhrt.org), the National Heart, Lung, and Blood Institute (www.nhlbi.gov), and the Mayo Clinic (www.mayo.edu) provide thorough and verifiable informational sources. All of these sites also provide additional links to other, related sites that can offer a more structured journey through the Internet maze.

To be effective, the so-called "decisive movement" of clinical care from the bedside to the Web site needs the clinicians' expertise and assistance. They can help patients uncover self management information that can be effective for these patients' specific at-home needs.

PROGRAMMABLE DEVICES, SUCH AS PERSONAL EMERGENCY RESPONSE SYSTEMS (PERS) AND PERSONAL DIGITAL ASSISTANTS (PDAs)

When the focus is on programmable devices, the division between self care for the ordinary consumer and that of the home health patient becomes quite blurred. Our percolators can be programmed to turn on and brew coffee at 6 am, our outdoor lighting at 9 pm, and emergency response teams know our elderly mothers' phone numbers if they push a pre-programmed button.

Convenience, security, protection—all are important issues, and all are getting attention in today's "smart" house and "smart" device designs.

PERSONAL EMERGENCY RESPONSE SYSTEMS (PERS). In home health care, safety is of utmost importance. Because a caregiver often cannot be present on a 24-hour basis, an emergency alert mechanism, like a single-signal button on a hospital bed, must be in place in the home. Personal Emergency Response Systems (PERS) have become widely used, particularly to help provide a virtual safety net (the ready 911 team) to elderly, disabled, and other homebound people who are alone at home.

Personal Emergency Response Systems—Virtual Safety Nets

Ever since the days when an actress dramatized the effect of an elderly person alone in a crisis situation ("I've fallen and I can't get up"), families and health care providers have recognized the value of having an electronic help system in the home. More than 100 companies today provide emergency alert systems, either as stand-alone devices or incorporated into wider ranging home security systems. Typically, a single button, a voice command conveyed to a wall-mounted or telephone-related mechanism, or even silence (when a patient's reply is expected) will prompt the device to perceive an emergency situation. These devices range from an electronic pendant or bracelet to a programmed phone system to various types of infrared and other sensors (the last of which are still in developmental stages for home health applications).

Standard PERS devices now available include:

*ELECTRONIC PENDANT/BRACELET WITH BUTTON SIGNALING DEVICES: These allow freedom of movement for the wearer. Example: The SOS system (from SOS Industries, 800-225-4848) stores a profile of emergency telephone numbers at its base station computer and in an emergency situation (when the button is pushed), help is automatically and electronically summoned as directed in the profile.

*PROGRAMMED AND/OR INTERACTIVE PHONE SYSTEM: Example: Lifeline (from Lifeline Systems, 800-451-0525) is a packaged telephone unit with large and illuminated numbered buttons designed to assist those with impaired dexterity or vision. The phone is multi-functional: it can be used as an ordinary telephone for usual purposes as well as for emergency alerts that are programmed and responded to by trained EMT personnel.

AND….PRODUCTS TO HELP AVOID EMERGENCIES IN THE FIRST PLACE—

Additional programmable tools that can help to keep people safe at home include consumer items that can be programmed to send particular alerts.

*THE VIBRATING ALARM/TIMER (from Potomac Industries, 301-762-4005), for example, is a digital alarm clock that has a beeping and vibrating mechanism that can signal a medication time for patients who are hard of hearing.

*THE DIGITAL AUDIO UNIT (from Clever Devices, 800-872-6129) is a digital, pre-recorded voice system that can interface with electrical signals from household or electronic devices to send similar medication reminder or other messages.

*And there is the TELEPHONE itself, which can be extended by products such as Safe-at-Home (Prisam Systems, 713-215-8199). This service can program household telephones to remind patients about drug regimes one or more times per day and speak in a voice selected by the patient (such as a friend or an adult child).

AND….PRODUCTS TO HELP IMPROVE SELF MANAGEMENT SO THAT PERSONS CAN CONTINUE LIVING AT HOME

Smart Houses: Making them "work"

A growing trend is the design and development of "smart houses."[5] A programming mechanism can enable coffee pots to start making coffee, in effect the mechanism "talks" to the coffee pot; and it can "talk" to the household lighting system so that some "know" when to turn on and off. The latest of entries: "smart" refrigerators. How smart? They will know us, the designers seem to be counting on, but know us in more ways than we may want. Large appliance companies are currently racing to perfect smart refrigerators which "know" what we eat and will remind/alert us when certain food items need replacing.

What's the bigger picture? For one, that no appliance or anything we take for granted as a single-function tool (keeping food cool, keeping its mouth shut, we hope, if we're eating too much Haagen Daas), is immune to re-engineering.

Eventually, every household and consumer item can probably become wired and "smart." In anticipation of this trend, we need to think about how and

what type of information can be communicated so that it will be more useful for home health patients we know. In our analysis, we need to concentrate on what should be said, by whom, and when. This process requires careful thought and customization that we will not get from general consumer items that are "smart."

PERSONAL DIGITAL ASSISTANTS (PDAS). These items, sometimes referred to as "handheld companions," are becoming among the most popular electronic items for ordinary consumers today. These are increasingly affordable, easier-than-ever-to-use handheld computers. They can help keep shopping lists, business appointments, and other reminders in order. Home health company clinicians are using them to enter and store inventory lists, schedules, and even maps to and from patients' homes.

Tomorrow's home care patient "companion"

One example includes:

> Encounter Technology Solutions (www.encountertechnology.com) features programming for 3C Palm Pilot III, IIIx, or V, and enables caregivers to perform all point-of-care visit recording tasks and download them; it can provide the caregiver access to up-to-date information about the patients and their records. The company suggests that because it is also easy and affordable enough to be used by aides and all field staff, it will promote more continuity in the maintenance of the electronic patient care record.

It is no stretch of the imagination to envision scenarios in which patients can extend their use of PDAs, too— for instance, they can use them to manage their daily, sometimes very complex medication reminders and directives. Why not use the devices for the patients' other scheduling needs, such as specialist appointments, perhaps with maps to give them driving directions on how to get to the specialist's office (with a back-up strobe light programmed to function from the patient's clock-radio to remind him when the date of the appointment is close at hand)?

When envisioning a future of talking refrigerators and smart coffeepots, smart and verbal PDAs seem to be just one part of the bigger picture for home self care (consumer or patient oriented). In fact, so many ordinary consumer items can have potential use in home healthcare that we can almost forget the distinct difference between people who use certain tools for simple convenience and people who rely on these tools for important healthcare needs. For example, with the help of these devices, a patient with diabetes can act just like anyone else living daily life. They may be drinking lemonade at 3 pm, and later in the afternoon, using what looks like an ordinary digital wristwatch, take a glucose measurement and finish off the day by preparing dinner at 6 pm.

Using programmable devices in the routines of daily care/life makes it seem as though this person no longer has an appendage, he's not a person "with a disease" but a person living ordinary daily life. New devices can make this person seem like any other consumer, with no special need. As we will discuss in the next section, a huge range of consumer products is readily available for purchase that could be of use to today's patients. Defining which of these products should be chosen and defining how they should be used for healthcare purposes is a more important task than ever before.

Trend: No more patients "with" diseases, only people

CLINICAL INSTRUMENTS, INCLUDING PERIPHERAL DEVICES AND WORKSTATIONS

Much of self care activity in home health today is focused on individual healthcare instruments that can assist in daily care routines. Home health equipment catalogs and Web sites offer peripheral devices such as blood pressure cuffs, glucometers, and other devices. Telecommunications-ready tools that can transmit blood pressure or glucose readings to a central tracking station usually are capable of connecting with a R232 serial port or an ordinary telephone outlet. The following two tables offer several examples of blood pressure cuffs and glucometers.

Company/Product	Features	Costs
A&D Engineering Med-Check	Auto-inflating cuff, downloads readings onto PC, "Pressure Log" software for trending and statistical analysis	$89.95 for cuff; $34.95 for Windows-compatible software
Shahal Medical TelePress	Push button, automatic self-pressurization device; systolic and diastolic values appear on a large liquid crystal display (LCD). Values are transmitted transtelephonically to a monitoring center for trending and analysis.	$155 + fees for offsite monitoring service

TABLE 5-1 TELECOMMUNICATIONS-READY BLOOD PRESSURE CUFFS

Telecomunications-ready tools

Company/ Product	Features	Cost	Telecommunications Capabilities
Boerhinger Mannheim AccuCheck glucose meters (manufactured in various versions)	AccuCheck Easy: Can store 350 glucose readings; can give patient average readings for one week. Can mark readings with special markers to denote readings taken before or after exercise. Company provides training, no home nurse or other technician required. Instructional video. 24-hour help desk service.	Kit is $75-85. Varies according to dealer and pharmacy rebate offers.	Third party software for Accucheck products is available via Internet. A Physician Data Management System product is for professional use only: cable from patient's glucometer can be attached to a computer, and data downloaded directly to a physician's office computer.
Lifescan One-Touch glucometer; In-Touch software	Can store 250 readings. Can provide 14-day summary of readings. Local pharmacists give demonstrations, training.	Meter: about $100; software: $100 or less, plus a home computer.	Downloads readings and graphs patient statistics. Can be transmitted to doctor's office via home computer and modem.

TABLE 5-2 TELECOMMUNICATIONS-READY GLUCOMETERS

Which product is most effective? Over time, trends in design and tool development have made it possible for all home health-packaged tools to be smaller, lighter, and easier to use. Some have multiple capabilities. Individual tools as well as full-scale workstations are being designed to operate as easily as using on/off switches or pressing a "Send" button.[6]

Regardless of progressive features and functionality, however, the job of clinicians remains the same—that is, choosing tools that are appropriate for particular patients. For example, one type of a telecommunications-ready blood pressure cuff may be too difficult to manage for a frail patient who lives alone. Clinicians need to locate products that meet special needs.

CASE

EXAMPLE:
The Accuchek Voicemate (from Roche Diagnostics/Eli Lilly, 312-240-2827) is an audio-assisted blood glucose monitor for the visually impaired. It can talk a patient through the process of obtaining a blood sample and provides tactile confirmation that blood is being placed on the correct spot of the testing strip.
This is an excellent example of company-directed development based on known market needs. (A percentage of the diabetic population may, in time, become blind.)

Another example of directed development of new tools was initiated by a home-care company:

CASE

EXAMPLE:
At the Cleveland Clinic Foundation Health Care Ventures, planners wanted their pediatric clients who needed ongoing infusion therapies to be able to manage a pre-programmed ambulatory pump when they went to school. The agency was using an infusion pump and bag that were too heavy for the children to carry, however. Agency planners solicited the help of an infusion pump manufacturer to design an easier-to-carry backpack that the children could manage. As another component of the arrangement, the manufacturer is developing a telecommunications capability, which is intended to help the children manage their therapy and pump.[7]

This development is a result of clinicians' taking an active role in helping the products "fit" their particular patients' needs. The range is large and growing, including stethoscopes, electrocardiograph monitors, videophones, charting tools, and more. A critical job of the clinician is to assess the patient's needs that can be met by telehealth tools (for example, a telecommunications-ready glucometer for a diabetic patient, not necessarily a full-scale telemedicine workstation or "solution") and what could "work."

Products that "fit"

Anyone who has followed higher-tech care and especially online care technologies or e-health has seen pronouncements that the point of care has moved from the "bedside to the Web site." This statement is (and should be) only partly true. Self management is a critical goal for patient care today, but some misunderstanding lingers about exactly what the term means.

For example, a person who performs in-home testing for HIV/AIDS, pregnancy, or other conditions, has begun a first step in self management. This is one important piece of the self-care puzzle. A second step may involve going onto the Web to seek more information.

According to many healthcare industry observers, today's more educated consumer seeking information on the Web and elsewhere is a new breed of patient. Regina E. Herzlinger, of Harvard Business School, contends that the driving force for tomorrow's changes in healthcare service delivery will be knowledgeable, pragmatic, empowered, and demanding baby boomers. As they age, she notes: "There's no reason for any rational person to believe that [the aged boomers] are going to say, 'Oh no, leave health care in the hands of these people who are going to tell me what to do.' Today's consumers simply won't accept that."[8] Clearly, providers will need to accommodate changes in their service delivery in response to these demands.

21st century home care patients—a new breed

Today's "new" consumer does have a certain curiosity and willingness to seek out information—this is one important piece of the self-care puzzle. However, a subsequent step in assembling that puzzle, and one that is still very

much part of self management, is conferring with a professional healthcare provider. Maintaining a certain degree of wellness and stability requires that patients become aware of the need for assistance and following through.

CONCLUSION

Products listed so for in this chapter could be the clinical building blocks for a long-term home care program. The list of products and applications is ever-growing. The telecommunications-ready infusion pumps, dialyzers, spirometers, and other products are making clear inroads toward retrofitting the typical living room into a one-stop healthcare shop. Some of the products have become packaged into full-scale, multifunctional workstations, while others are stand-alone items. There is the opportunity with all of these choices for providers to select which ones are needed, do the packaging, work to make them fit, try to make them work.

Packaging the tools and complementary instructional materials into customized suites is a challenge. In the next section, we suggest a range of tools and services for one patient care group, the escalating numbers of patients with pediatric asthma. This suggested range may well provide a template that could be used for identifying and customizing arrays of tools/interactions for other chronic disease patient groups, such as those with diabetes and heart disease.

PEDIATRIC ASTHMA PATIENTS AND THEIR NEEDS: A SAMPLE OF TARGETED PROGRAM BUILDING BLOCKS

Pediatric asthma today

Asthma currently affects an estimated 15 million Americans, including more than 5 million children.[9] Costs of this population are about $14 billion per year, much of this cost associated with emergency room treatments and hospitalizations. Among children, the need for hospitalization has increased 5 times the rate estimated in 1980. It is a preventable disease, experts say, but it is reaching epidemic numbers nonetheless. Asthma rates have increased in children up to 160% since 1980.

Prevention of symptoms which lead to asthmatic episodes is perceived as key to all efforts to educate patients and their parents. Identifying and avoiding/managing "triggers" that lead to the onset of asthma attacks are critical in educational efforts. These triggers are environmentally based and include dust, air pollution (including cigarette smoke), mold, and insects. Educational programs focus on identifying tools and routines to help patients manage and avoid these triggers. Knowing how to control symptoms or exacerbations can prevent a family's race to the hospital emergency room.

SELECTED TELEHEALTHCARE AND OTHER TOOLS FOR PEDIATRIC ASTHMA PATIENTS MANAGEMENT

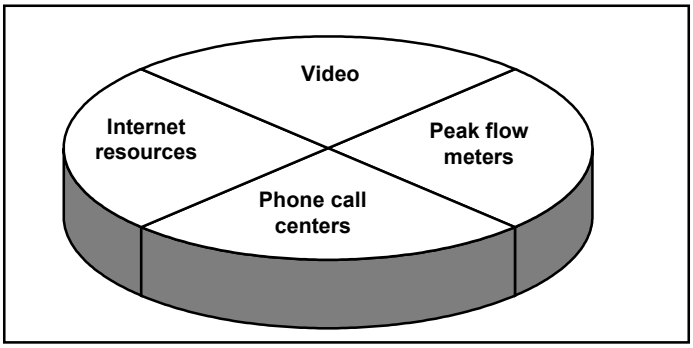


Figure 5-1. Pediatric Asthma Management Tools

Some useful resources that can help agencies extend their services both to children with pediatric asthma and their parents include:

For Children

Beyond the informational brochure—

Videos, Internet sites/Chat Rooms, Workbooks are some of the educational tools produced for children with asthma.

- **The Asthma & Allergy Foundation of America** produces the following resources for children:
- Kids Club House: A CD-ROM for learning about asthma
- Bronkie the Bronchiasaurus: a Nintendo game adventure in which children players manage the asthma of 2 dinosaurs

800-7ASTHMA/ www.aafa.org/

- **Allergy/Asthma Tech, Ltd**. Offers The Kids Only Area on its product-focused Web site: http://allergyasthmatech.com/
- One of its products is an interactive CD-ROM called "Asthma Explored," ($19.95). See either the Web site, or contact: 1-800-621-5545.

Figure 5-2 Pediatric Asthma: Resources for Children

Peak Flow Meters

Lifechart.com (includes the Airwatch peak flow meter) (650-867-0379) is among the few companies that now manufactures stand-alone peak flow meters that have a telecommunications capability. This feature enables physicians to track asthmatic patients more regularly and respond expediently.

It can also be used in combination with teaching resources, such as those available from **The Asthma & Allergy Foundation of America** (see above section), which produce color-coded materials for asthma control (green-go, yellow- caution, etc.) and describe how asthma should be treated in each zone.

For Parents and Other Family Members

Videos/Written and Online Information reinforced by phone/visiting services

A range of information is available which can reinforce directives/messages about care for children with asthma. Especially:

- **Videos:** such as several from the **Allergy & Asthma Network- Mothers of Asthmatics, Inc.** include: a 24-minute overview titled "Managing Childhood Asthma," and another called "Exercise and Asthma." (www.aaamaorg/)

- **Written and online information** is available from the **American Lung Association,** regarding patient management plans (how often bedsheets need to be changed, for example). www.lungusa.org/ 800-586-4872.

Johns Hopkins' Health Information Network (www.intelihealth.com), provides excellent informational materials for parents of children with asthma, including lists of advice, medication explanation charts, a personal diary and tracking tool, and an "Ask the Doc" capability for questions and answers.

- **Phone services** dedicated to respiratory problems include the nurse-staffed **LungLine** (National Jewish Medical and Research Center) 800-222-LUNG.

- **The Allergy & Asthma Network- Mothers of Asthmatics, Inc.** has a toll-free informational hotline: 800-878-4403. In addition, this organization produces a regular 8-page newsletter, in which physicians address particular concerns of parents of asthmatics, such as the effects of chickenpox during the use asthma medications, and non-medical ways to help asthma patients.

Figure 5-3 Pediatric Asthma: Resources for Parents

Another option to complement conventional services to pediatric asthma families:

> **Trained lay people/assisters** may help to extend nurses' services to difficult-to-reach clients. A home care program in Philadelphia reports its use of trained community workers to visit asthma patients' homes, relying on their assistance when cultural barriers prevent usual monitoring of patients' medical care directives. The laypeople's role is to "reinforce the reach of the [home care] nurse and act as a go-between." [10]

Needed care assisters/ extenders

Reaching out into the broader community is an option that providers must investigate when they need help in reaching their patients. For example, the trained laypeople who enter the homes of their own cultural groups in Philadelphia can be of assistance. An effort now underway in New York City's East Harlem, where asthma levels are extremely high, provides another useful example.[11] In addition to usual home care services, through funding by a federal government grant, an environmental specialist has been engaged to enter the homes of pediatric asthma patients to show the families how to deal with infestations, which can be asthma triggers. Other interventions will include distribution of nontoxic pesticides for the same educational/preventive purposes and of nicotine patches to family members who smoke. These intervention efforts highlight the importance of managing the home environment.

No agency, clearly, can provide all of the needed services for any chronic disease patient group—new tools and new care team participants can augment conventional care and do so on an as-needed basis. More contact rather than less (especially in the early phases chronic disease patient-care programs) reinforces educational messages and routines for self management. It's a long-term approach for patients who need a lifetime of care.

HOME SELF-TELECARE: THE CONTINUING CHALLENGE

The critical value of using the home telecare enabling devices described in this chapter is that they help patients to act and live independently to the extent that they are capable. They can live their lives having more control over their day-to-day activities. This approach involves more than just enabling patients to send glucose data or peak flow measurements, though—it offers them a new way to take part in the routines of chronic disease patient life. The following example demonstrates how one patient used telecare products to meet her own very personal and important daily needs:

CASE EXAMPLE : **CASE**

Being a cancer patient, being a mom, being a wife...[12]

An interesting twist on delivery of care and support via tele-videoservices: at St. Joseph's Cancer Institute in Tampa, Florida, a desktop videoconferencing system has enabled patients undergoing cancer treatments in isolated therapy rooms to "televisit" with their families in their own homes, which are often at some distance from the Institute. In one case, a mother with cancer uses the system to help her children with their homework. She may also provide advice about menu planning, and otherwise supervise household activities.

Other applications– practical, therapeutic, and more–by cancer patients and others using a televideo system may well be as varied as their own individual conditions and needs require.

The possibilities are countless, but we must start doing more than counting.

The changing, more restrictive environment of home care financing has left providers little choice but to investigate alternate means of care delivery and to make plans for their use. A likely option is the use of consumer devices that can supplement and extend conventional (and now less affordable) home care services. These devices now comprise a burgeoning industry into itself—easier-

to-use hand-held planners, affordable cell phones, accessible information kiosks in supermarkets and airports. Even more devices, venues for services, and new formats for information will become familiar items that can potentially be used to deliver some form of healthcare services. (And more than a few more will claim to provide home health "solutions.")

But, without question, one continuing challenge for home care providers today and tomorrow will be harnessing the undoubtedly growing wave of telecare tools, applications, and information that will be more readily available in the near future. They need to make sense of it, for their businesses, and for their patients. Providers will need to assess each item and use each as building blocks in the design and re-design of targeted self-care programs for particular patients. The goal: helping those patients who are capable of using telecare assistance to proceed safely along the path toward effective self management. Home care planners, device designers, and the patients themselves now each have critical roles to play on the path to this necessary, focused destination of long-term patient self management; all of them need to participate to make telehealth and self care "work."

The telecare plan– a work in progress

NOTES

1 Observations on typically lower-tech individuals who are in the home today are discussed in A. Kinsella (Jan. 2000). "E-health and this generation of home care patient." Home health segment, the Telemedicine Information Exchange (http://tie.telemed.org)

2 Institute for Health and Aging [Univ. of California at San Francisco] 1996. *Chronic Care in America: A 21st Century Challenge*. Princeton, NJ: The Robert Wood Johnson Foundation; and Hoffman, C, D Rice, and HY Sing (1996). "Persons with chronic conditions: their prevalence and costs." *JAMA* 286 (18): 1473-1479.

3 Sources: Kinsella, A. (1998). "Managing the inner city." *Home Health Care Dealer* May/June: 75-76; telephone interviews by the author with Tom O'Mara, VP Marketing, UniTech Technologies (Dallas, TX), Mar. 10, 1998; Eliott Soloway, Department of Engineering, University of Michigan, Jan. 22, 1998; Susan Morrell-Samuels, School of Public Health, Univ. of Michigan, Mar. 10, 1998.

4 See, for instance, Stevens, L. (1999), "Net reception," *American Medical News*, Oct. 11: 34-35, on physicians' role in helping patients usefully understand healthcare information that the patients have gleaned from the Net.

5 See, for example: Webb, W. (July 1999)"Living with dumb houses," available at: www.ednmag.com/reg/1999/070899/14ed3.htm; Warren, S. et al (March 1999), "Designing smart health care technology into the home of the future," Background paper for Home Care Technologies for the 21st Century; available at: www.hctr.be.cua.edu/HCTworkshop (under Paper Archive); Arent, L.(1999) "Patients heal thyselves," *Wired News* (at: www.wired.com/news/news/technology/story/19776.html)

6 Kinsella, A. (Mar 1999) "Home care technologies 1999: Movement toward the home as a one-stop healthcare shop." Background paper for Home Care Technologies for the 21st Century; available at: www.hctr.be.cua.edu/HCTworkshop (under Paper Archive)

7 Mark Sucheck, Director of Pharmacy, Cleveland Clinic Foundation Home Care Pharmacy, Valley View, OH, telephone interview with the author, July 7, 1997.

8 Quoted in Mullen, P. (1998). "A conversation with Regina E. Herzlinger," *Managed Care*, May: 41; more details are in Herzlinger, RE (1997). *Market-driven Health Care: Who Wins, Who Loses in the Transformation of America's Largest Service Industry.* (Reading, MA: Addison Wellesley). The title of the first of 4 sections, for instance, is "What Consumers Want: Convenience and Mastery."

9 Sources: Centers for Disease Control (1997). "Asthma surveillance programs in public health departments-US. *MMWR,* Apr 24: 2-12; Moyer, P. (1997). "Asthma care: new treatment strategies, new expectations." *Patient Care,* Oct. 15: 82-100; Stapleton, S. (1998). "Asthma rates hit epidemic numbers; experts wonder why." *American Medical News*, May 11: 5.

10 Unsigned article (1997) "Use peers to locate, educate patients," *Homecare Quality Management*, Feb.: 20-21.

11 Shelton, D. (1999), "Finding ways to fight asthma in kids," *American Medical News*, Nov. 15: 28.

12 See, for example, an unsigned article, "Desktop video system enables cancer patient to visit with her family while undergoing treatment in an isolated pressurized environment," BusinessWire, Feb. 13, 1996.