A Caregivers Guide to Coordinating Medical Care

VNA COMMUNITY HEALTHCARE & HOSPICE
BESIDE YOU AT EVERY TURN

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Medical Care Coordination

WHAT IS "MEDICAL CARE COORDINATION"?

Organizing medical care activities and information to get the best possible health results for the person you are helping.

3 STEPS TO GOOD CARE COORDINATION

STEPS TO STAY ORGANIZED

1. Keep track of medical information
2. Navigate the health system
3. Manage your insurance
4. Maintain medication lists and refills
5. Plan ahead with advance directives

THINGS YOU SHOULD TRACK

- Appointments

- Provider contact information

- Test results

- Internet passwords

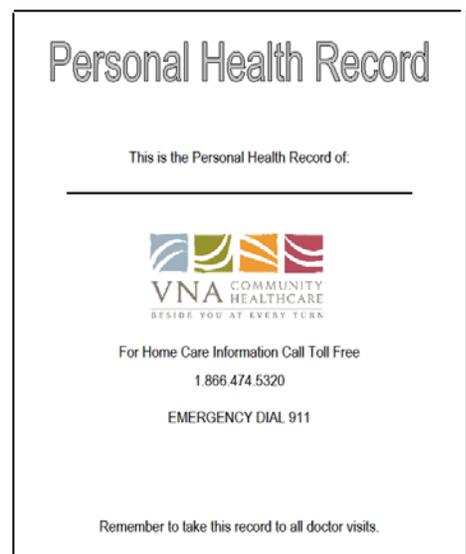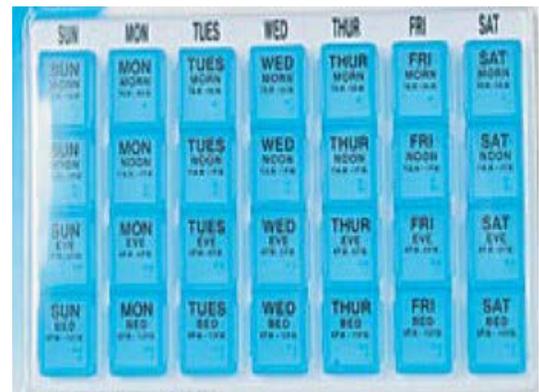- Insurance paperwork

- Visit and phone call notes

- Medications

ESTABILSH GOOD COMMUNICATION:

Building a good relationship with our physicians and those who provide care is a critical component in making sure you get the care you want. Healthcare notebooks are a valuable tool used to combine vital information which can be shared between all healthcare providers. Coordination among healthcare professionals is essential.

TOOLS FOR ORGANIZING MEDICAL CARE

- Smart phone, tablet or computer

- Calendar

- Notebook

- Personal health notebook

- Medical care coordination software

- Medication chart

- Medication boxes or dispensers

- Envelopes for insurance receipts

- Medical test file

- Insurance benefit booklet

- Online medical record passwords

Personal Health Record

This is the Personal Health Record of:

_____

VNA COMMUNITY HEALTHCARE
BESIDE YOU AT EVERY TURN

For Home Care Information Call Toll Free
1.866.474.5320

EMERGENCY DIAL 911

Remember to take this record to all doctor visits.

HOW A PERSONAL HEALTH NOTEBOOK CAN HELP:

- Maintains an up-to-date ongoing record care, services, providers, and notes

- Helps maintain lines of communication between the multiple providers

- Medical offices can make copies of your files / notes / reports

- Helps prevent duplicate testing and allows "another set of eyes" to view results

- Helps providers gain a better understanding of the patient's medical condition

- Encourages active participation of caregivers and patients

- Gives healthcare providers a similar understanding of the patients status when transitioning from one setting to another

- Great for short notice visits, new doctor visits, and second opinions

- Assists with coordination and continuity of health care

NAVIGATE THE HEALTH SYSTEM

- Use your primary care doctor for most things

- Specialists for complicated illnesses

- Save the ER for real emergencies

- Always check insurance

- Find reliable resources

MANAGE INSURANCES

• Track copays and deductibles	• Get required approvals
• Show the most recent card	• Investigate travel rules
• Read the coverage list	• Use plan discounts
• Learn the appeals process	• Use nurse lines for advice
• Use participating providers	• Participate in disease management programs

HAVE THE HARD CONVERSATIONS

- It is difficult to think ahead about the end of life's difficult choices.

- It is important to have those difficult talks to make sure wishes are carried out and to prevent the family from having to deal with hard choices without information.

- The "Five Wishes" or the "Conversation Project" is programs designed to help make this conversation easier.

- At the end of this booklet is a glossary that contains list of terms that will help in this process.
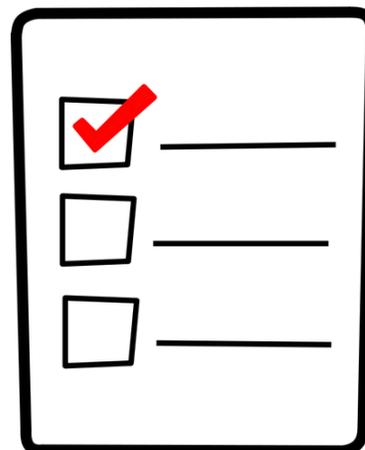
ORGANIZING MEDICATIONS

- Keep medication lists updated

- Keep up with refills

- Organize medications in one place

- Use bill boxes or dispensers

BE A HEALTH CARE ADVOCATE

- Go to all medical visits with your relative

- Make a list of health concerns

- Bring current medical information

- Ask good questions

- Write down instructions

COMMUNICATION TIPS

- Set the stage

- Be clear about what you want

- Ask "what if" questions

- Ask questions about medical finding and treatment choices

- Clarify instructions before you leave

THE ESSENCE OF CARE COORDINATION

Information flows with the patient

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Professionals communicate

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Nothing falls through the cracks
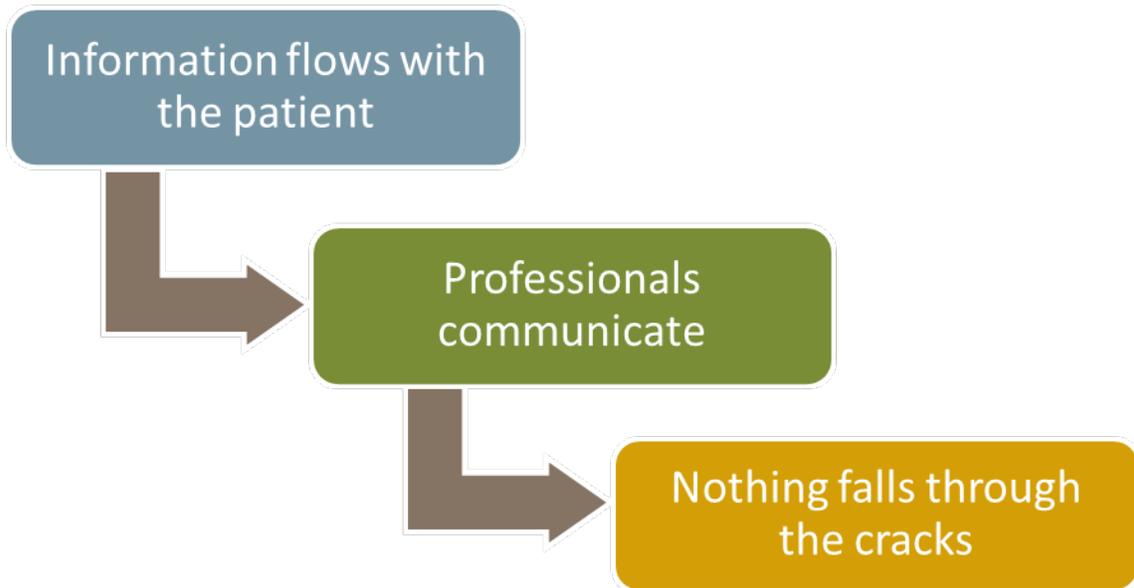
YOU ARE THE GLUE that keeps things together!

GLUE

High risk situations for breakdown in communication:

- Emergency Room visits
- Hospital Admissions
- Shift or doctor changes in the hospital
- Hospital or nursing home discharge
- After a medical procedure or one day surgery
- Discharge from home health care
- Multiple "care coordinators" calling

COORDINATE CARE COORDINATORS

If you get a call from a "care coordinator":

1. Write his/her name and phone number

2. Ask what organization they represent

3. Find out why they are calling

4. Find out how they can help you. If they can't, politely refuse to talk, if you don't want to

CAREGIVER SURVIVAL RULES

- Care for your own health

- Get an outside perspective

- **Ask for help**

- Rest

- Laugh

- Join a support group

- Focus on accomplishments

GLOSSARY

☐ **ADVANCE DIRECTIVE:** also known as living will, personal directive, advance directive, or advance decision, is a set of written instructions that a person gives that specifies what actions should be taken for their health, if they are no longer able to make decisions because of illness or incapacity. A living will is one form of advance directive, leaving instructions for treatment.

☐ **DO NOT RESUSCITATE:** "**DNR**", is a legal order written either in the hospital or on a legal form to respect the wishes of a patient not to undergo CPR or advanced cardiac life support (ACLS) if their heart were to stop or they were to stop breathing. The DNR request is usually made by the patient or health care power of attorney and allows the medical teams taking care of them to respect their wishes. A DNR does not affect any treatment other than that which would require intubation or CPR. Patients who are DNR can continue to get chemotherapy, antibiotics, dialysis, or any other appropriate treatments.

☐ **COMFORT CARE: Also known as Palliative care** focuses on relieving and preventing the suffering of patients. Unlike hospice care, **palliative medicine** is appropriate for patients in all disease stages, including those undergoing treatment for curable illnesses and those living with chronic diseases, as well as patients who are nearing the end of life. It utilizes a multidisciplinary approach to patient care, relying on input from all disciplines providing care and is structured to relieve suffering in all areas of a patient's life. This approach allows the team to address physical, emotional, spiritual and social concerns that arise with advanced illness. Medications and treatments are said to have a palliative effect if they relieve symptoms without having a curative effect on the underlying disease or cause. This can include treating nausea related to chemotherapy or something as simple as morphine to treat the pain of broken leg or ibuprofen to treat aching related to an influenza (flu) infection.

☐ **HEALTH CARE PROXY:** is an instrument (or document) that allows a patient to appoint an agent to make health care decisions in the event that the primary individual is incapable of executing such decisions. Once the document is drafted, the primary individual continues to be allowed to make health care decisions as long as they are still competent to do so. They allow a patient's wishes to be followed even when he/she is incapable of communicating them. In many jurisdictions, a health care proxy is closely related to a "springing" health care power of attorney; with many practitioners using these two terms interchangeably.

☐ **POWER OF ATTORNEY** is a written authorization to represent or act on another's behalf in private affairs, business, or some other legal matter, sometimes against the wishes of the other's.

☐ **HEALTH CARE POWER OF ATTORNEY:** In some jurisdictions, a durable power of attorney can also be a "health care power of attorney." This particular affidavit gives the attorney-in-fact the authority to make health-care decisions for the grantor, up to and including terminating care and life support. The grantor can typically modify or restrict the powers of the agent to make end-of-life decisions. In many jurisdictions a health care power of attorney is also referred to as a "health care proxy" and, as such, the two terms are sometimes used interchangeable.

WHERE TO LOOK FOR RESOURCES

- Federal and state agencies

- UCONN personalized health information   research program

- 211 for community resources

- Consumer Reports *Choosing Wisely*

- Agencies on Aging

- On the internet – look for reliable sites

TOP SOURCES OF INTERNET SENIOR INFORMATION – FROM THE MEDICAL LIBRARY ASSOCIATION

The AGS Foundation for Health in Aging
http://www.healthinaging.org

Health in Aging provides up-to-date information on healthcare and aging for older adults, caregivers, and providers. The site provides information and tip sheets on common health topics and resources to help find and communicate with geriatrics healthcare providers. Information is easy to understand and available in English only. The site was created by the American Geriatrics Society's Health in Aging Foundation and is overseen by elder care experts.

Benefits Checkup
https://www.benefitscheckup.org/

Benefits Checkup is services aimed at helping older adults find state, federal, and private benefits programs to help pay for prescriptions, healthcare, food, and other services. Older adults can answer a series of questions and receive information and applications for programs for which they may be eligible. The site also contains links to forms and resources for local and national programs. Information is in English, although many forms are available in multiple languages. The site is a service of National Council on Aging, a non-profit and advocacy organization for older adults.

Centers for Disease Control's Healthy Aging

http://www.cdc.gov/aging/

This site provides statistics and research information from the CDC's activities aimed at improving the health and quality of life of older adults. Resources include information about the Healthy Brain Initiative, advance care planning and chronic disease management, and links to publications and resources for both consumers and health professionals. The information is available in English.

Eldercare Locator

http://www.eldercare.gov/

Eldercare Locator, service of the U. S. Administration on Aging, connects older adults and caregivers to services for seniors. The online search function provides lists of trusted local resources, organizations, and services. There are also factsheets and links to online information about medicine and health, advanced care planning, and other issues. A hotline and online chat connects to Eldercare information specialists who can answer detailed questions. Online information is available in English; information in other languages is available by phone.

The Family Caregiver Alliance

http://www.caregiver.org

Family Caregiver Alliance (FCA) provides information, services, and support for caregivers and families of persons with chronic, disabling health conditions. The website offers fact sheets on conditions such as dementia, Parkinson disease, and stroke as well as statistics, public policy information, and reports. It includes caregiver advice and tips and hosts online discussion groups. Information is available in English, Spanish, Chinese, Korean, and Vietnamese. The FCA is a nonprofit, community-based organization.

Medicare.gov

http://www.medicare.gov/

The official U.S. government website provides a wealth of information on Medicare health plans, drug coverage, and costs. It also offers tools to find whether a test, item, or service is covered and for finding doctors, providers, hospitals, plans, and suppliers. Online forms are provided for applying to the program, replacing a Medicare card, or changing an address. Information is available in English and in Spanish.

MedlinePlus Seniors' Health

http://www.nlm.nih.gov/medlineplus/seniorshealth.html

The Seniors' Health section of MedlinePlus contains links to reliable health information throughout the web including the latest news, overviews of senior health issues, research, statistics, aging organizations, clinical trials, and more. Links also guide you to pre-formatted article searches on PubMed. Information is easy to understand and available in English and Spanish. Information comes from the National Library of Medicine.

National Institute on Aging

http://www.nia.nih.gov/

National Institute on Aging (NIA) leads a broad scientific effort to understand the nature of aging and to extend the healthy, active years of life. The website includes information and tips on health and aging, with a large section on Alzheimer's disease, as well as information clinical trials and the latest research. Information is available in both English and Spanish. Free print version of fact sheets and brochures are available for ordering. The NIA is a part of the National Institutes of Health.

National Resource Center on LGBT Aging

http://www.lgbtagingcenter.org/

The National Resource Center on LGBT Aging is aimed at providing resources to help improve the services and support available for lesbian, gay, bisexual and transgender (LGBT) older adults. The website provides a wealth of articles about topics ranging from general health and aging concerns to the particular legal and social issues facing LGBT seniors. A directory for state-based resources and information about training for caregivers and healthcare providers is also available. Information is available in English and Spanish. The site is a project of SAGE, the nations oldest and largest nonprofit focused on LGBT seniors.

NIH Senior Health

http://nihseniorhealth.gov/

This National Institutes of Health website for older adults makes aging-related health information easily accessible for those seeking reliable, easy to understand online health information. Well-illustrated and readable, it includes many short videos, tutorials, and links out to other sites for additional information. It also allows increases in contrast as well as size of type for easier viewing. Information is available in English only.

Top Sources of Reliable Internet Medical Information – from the Medical Library Association

Aetna Intelihealth
http://www.intelihealth.com/

Aetna InteliHealth, a subsidiary of Aetna, partners with Harvard Medical School and Columbia University College of Dental Medicine to provide health information on this website. Content rich on disease and treatment information, this site includes additional features, such as interactive health tools, Ask the Expert, dental health, a medical dictionary, and a drug resource center. The focus is on healthy lifestyle choices. It's important to note that Aetna InteliHealth's editorial policy states that it maintains absolute editorial independence from Aetna.

Centers for Disease Control and Prevention
http://www.cdc.gov

The CDC, a part of the U.S. Department of Health and Human Services, aims to prevent and control disease, injury, and disability. Its website ably reflects this mission. One of the best government websites on the Internet, its coverage is broad. The "Diseases and Conditions" section covers major chronic and many infectious diseases, including AIDS, bird flu, common childhood diseases like measles and more exotic diseases like Ebola. Birth defects, traveler's health, emergency preparedness, vaccine and immunization information, accidents and injury information, infectious diseases, and workplace safety and health -- all are covered on this comprehensive site. Rich in information and colorfully illustrated, it also provides information in Spanish. Special features are regularly updated, and health news articles are added daily.

The Cleveland Clinic Health Information Center
http://my.clevelandclinic.org/health/default.aspx

Produced by the Cleveland Clinic to benefit patients, the general public, and healthcare professionals, this site offers nearly 5,000 articles, videos, podcasts and tools for managing your health. A Health Information Search Specialist can answer questions via a live chat service Monday through Friday, 10:00 am to 3:00 pm EST (except holidays). Visit the online learning center to improve your knowledge of specific diseases, conditions, and treatments. A symptom checker and links to free guides and newsletters are included on the site.

Familydoctor.org
http://familydoctor.org/familydoctor/en.html

The content on FamilyDoctor.org is intended for individuals who are seeking reliable health information written at a 6th-8th grade reading level. Children, teens, and seniors can explore sections specifically for them. All information has been written and reviewed by physicians and patient education professionals at the American Academy of Family Physicians.

healthfinder

http://www.healthfinder.gov/

Managed by the U.S. Department of Health and Human Services, healthfinder.gov provides reliable information culled from approximately 1,400 health-related organizations. Features of note include tools for finding health services and support, National Health Observances toolkits, and information about health care reform. Use the "en Español" link to find a mirror site in Spanish.

Mayo Clinic

http://www.mayoclinic.com/

MayoClinic.com offers a wealth of easy-to-understand health and medical information. In addition to comprehensive disease and condition guides the site includes descriptions of drugs, supplements, tests, and procedures; healthy living guides; a symptom checker; and expert blogs.

MedlinePlus

http://www.medlineplus.gov

The National Library of Medicine, a part of the National Institutes of Health, created and maintains MedlinePlus to assist consumers in locating authoritative health information. The first place to go when seeking information MedlinePlus pages offer carefully selected links to web resources with health information on more than 900 topics. The A.D.A.M. medical encyclopedia includes images, videos, and over 4,000 brief articles. Drug and supplement information, a medical dictionary, and patient education interactive tutorials are also provided. The Español button allows searching the site in Spanish, and the Multiple Languages section allows searching in over 40 other languages.

Merck Manual Home Edition for Patients and Caregivers

http://www.merckmanuals.com/home/index.html

Based on the widely used textbook of medicine, the online edition of the Merck Manual is written in everyday language and contains photographs, audio and video material. Other helpful features include first aid information, common medical tests, a drug names table, and links to other reliable resources and information.

NetWellness

http://www.netwellness.org

NetWellness, a nonprofit consumer health website, provides more than 55,000 pages of high quality information created and evaluated by medical and health professional faculty at the University of Cincinnati, Case Western Reserve University, and the Ohio State University. Its "Ask an Expert" feature is a question and answer service provided by numerous health care professionals of the three universities. The "Reference Library" section provides links to other carefully selected health sites, and the "Research" section provides access to information about the latest medical research.