Health Advocacy Tips for Family Caregivers and Care Recipients

An Educational Program of the National Family Caregivers Association
Today’s program is designed to better prepare you and your loved ones for dealing with chronic health issues such as spinal cord injury, MS, polio, ALS or spina bifida:

- Communicating with healthcare professionals
- Becoming a strong advocate in healthcare situations
- Preventing medication mishaps
The Voice of the Caregiver

- Family Caregivers and their loved ones are the only people present across all care settings.
- Family Caregivers have an intimate knowledge of the patient.
- Family Caregivers have the desire to make sure their loved one is as healthy and has as high a quality of life as possible.
- Family Caregivers see the patient in their own homes and for a longer period of time than anyone in the provider community.

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The Voice of the Care Recipient

- Join your family caregiver as a member of your own healthcare team
- Manage your medications
  - Be both adherent and compliant
- Communicate effectively
- Keep track of symptoms, medications, and appointments
- Deserve information on their condition, and available treatments
- Coping with costs, and challenges associated with their healthcare needs

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Good Communication

Healthcare Professionals

Positive Outcomes

Family Caregivers

Better care for patients

Less stress for family caregivers

More efficient use of everyone’s time

Greater satisfaction for all concerned

Reduced costs for insurers, hospitals and OOP for patients/families

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Patient File

The best way to achieve clear communication and to function effectively as a team is to create and maintain a comprehensive file of information about the care recipient.

Checklist contains:
- Personal medical record
  - Diagnosis
  - Physician Contact Information
  - Medications
- Allergies
- Health history (e.g. surgeries, other medical conditions)
Patient File (cont’d)

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<th><strong>Legal Information and documents</strong></th>
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Preparing for the Medical Office Visit

- Review medical changes since last visit.
- Prioritize and write down primary concerns and questions (e.g. pain, drug interaction, diet issues). Bring to visit.
- Ensure completion of all required tests (e.g. blood work, scans, etc.) in advance.
Following the Medical Office Visit

Recap the meeting, prioritize the important issues, write them down, and provide to the care giving team:

- Overall health status
- Disease status
- New or discontinued medicines
- Upcoming tests
- Things to watch out for: side effects, changes in eating habits, temperament, energy levels, etc.
- Help you might need in the near term
Preparing for the Emergency Room Visit

- Be prepared to report symptoms clearly
- Bring an up-to-date medication list and medical history
- Pack a bag of essential supplies
CAREGIVERS: While at the Emergency Room

- Introduce yourself, including your relationship to the patient
- Convey needed information
- Stay out of the way, but remain close by
- Inquire about the frequency of patient condition updates
- Calmly interact with the patient and staff
- Express your thanks
Prevent Medication Mishaps

- People with chronic illnesses or conditions take more medications than anyone else

Source: Medical Expenditure Panel Survey, 2006
When are Medication Problems Most Likely to Occur?

When...

- The prescription is written
- The prescription is filled or re-filled
- Changes in medical condition
- Transitions in care and care settings
- Seeing multiple providers
- Using multiple pharmacies
- Taking multiple medications
- Prescriptions are not taken as directed
- Prescriptions are not taken at all
- Prescribers/pharmacists are unaware of over-the-counter medications, herbals and supplements being taken
What can Caregivers do to avoid a negative Rx Experience:

- Maintain an up-to-date medication list. Do what’s easiest for you:
  - Create your own form
  - Use forms from the internet
  - Use computers/technology

- Where to keep the list:
  - In you wallet/purse
  - On the fridge (especially if loved one is homebound)
  - In patient file
  - On a flash drive

- Know why a medication is being prescribed and what it is supposed to do.
- Don’t take anything for granted – ask lots of questions.
What can Care Recipients do to avoid a negative Rx Experience:

- Join your family caregiver as a member of your own healthcare team
- Manage your medications. Be both adherent and compliant
- Communicate effectively
- Personal Health
For More Information
Additional materials available by visiting
www.spinalcord.org
and clicking on Webinar Archive
Questions

To ask a question or make a comment please type it in the “Questions” box
“Staying Healthy Together”

We are committed to supporting the caregiver and care recipient community with the tools and resources to focus on what's most important – Your health!

Contact Information: Mark Gibbons, mark.gibbons@thefamilycaregiver.org

Thank You!