

Supported Decision Making in Later Life

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Supported decision making (SDM) is a Person driven or Person centered model that empowers a Person with limited or declining capacity to make choices with guidance and advice from trusted advisors. SDM states the principles that all individuals, as long as they are able to communicate, have a fundamental ability and right to make choices and life's decisions that adults normally engage advisors to assist with and that the choices of the individual should be honored.ⁱⁱ SDM gained traction in advocacy for adults with disabilitiesⁱⁱⁱ and is expanding as a model for helping older adults experiencing changes in memory and cognition.

SDM is a balancing point between leaving a Person totally on their own, and someone taking control of the Person's life.^{iv} SMD requires advisors or a supportive circle to work with the Person to offer advice and guidance to assist the Person in making choices. The advisors are tasked with explaining the facts and issues, offering advice, making recommendations and guiding choices – always in consultation with the Person; and then honoring the choices of the individual. We all practice SDM in our daily lives. When we are sick, we ask medical

professionals for a diagnosis and advice and make a choice on the treatment we want or do not want based on that information.

When we take our cars in for service, the “service advisor” makes recommendations on work to be done, and we make choices based on that advice. We select advisors be they doctors, mechanics, bankers or plumbers based on how they treat us and how we feel about their advice. As adults we engage in supported decision making all of the time.^v We also have a right to ignore the advice and make what others may see as bad choices. At one time or another most of us have ignored the advice of a doctor, or chosen not to have that 30,000 mile scheduled service done on our car. We have all spent money in ways that others considered wasteful or foolish – as adults we are allowed to do that. These are rights and

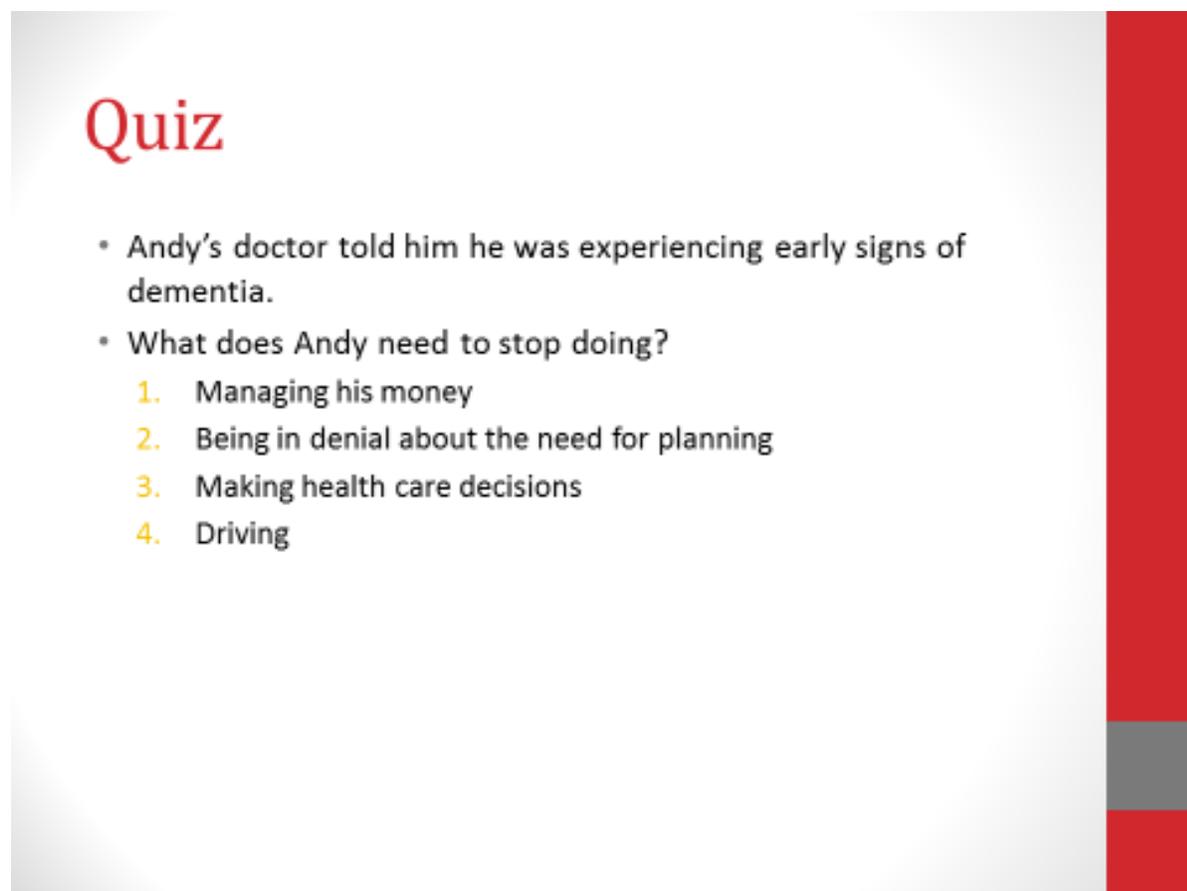


Person or person

The focus of supported decision making is on the individual. If I referred to the individual as David or Mary, I would capitalize the first letter of the name, recognizing that I am referring to an individual human being. I capitalize Person, to remind us that the focus is on an individual human being. This usage is awkward, and in many cases grammatically incorrect, the goal is to focus the readers on the humanity of the Person.

choices that should not be taken away from a Person, just because the world perceives the Person as being different.

Yet, for adults with disabilities and for adults experiencing changes in memory or cognition – developing dementia, the norm has been to take over decision making for them. We over react by trying to protect adults from their choices. Utilizing the SDM model empowers the adult to remain active in the decisions impacting their lives. For adults experiencing changes in memory and cognition, the SDM model can play an important role in planning, selecting advisors and legally empowering advisors.



Quiz

- Andy's doctor told him he was experiencing early signs of dementia.
- What does Andy need to stop doing?
 1. Managing his money
 2. Being in denial about the need for planning
 3. Making health care decisions
 4. Driving

Early Diagnosis – Early Planning

Early diagnosis of dementia improves options for legal planning and treatment. A Person can have a lot of residual capacity at the time of diagnosis. As understanding of the causes of

dementia expand, and treatment options emerge for some causes, there is an expanded push for early diagnosis.^{vi}

While we urge every adult to plan for incapacity, planning becomes critically important for a Person experiencing changes in memory and cognition. To engage in planning, planning must take place while a Person has the ability to understand and make choices. Dementia will progress to the point that planning is impossible. Early diagnosis of dementia needs to be a trigger point for selecting and legally empowering advisors to assist with personal, health and financial decisions. The sooner the Person engages in planning, the greater the likelihood that the Person will have the legal capacity needed to do so.

Planning for Finances

Frequently the first sign that a Person is experiencing changes in memory or cognition, is unpaid bills, or income not being deposited. Remembering to take checks to the bank and write checks to pay the bills, requires memory and decision making. Planning makes it possible to leave directions on how you want this to be done, who can help with it, and to legally empower the Persons chosen to help with these tasks.

Direct Deposit of Income

Nearly all recurring or periodic income can and should be set up on direct deposit. Social Security has moved virtually all beneficiaries to direct deposit.^{vii} Pensions, distributions from 401k, dividends, and interest payments should all be set up on direct deposit. As attorneys and advocates we need to counsel clients to take advantage of direct deposit. Finding unopened mail and un-deposited checks is very common when working with clients with dementia. The goal here should be for all income to be directly deposited, so that bills and expenses can be paid.

My parents came home from lunch one day and the electricity had been turned off for non-payment. For 60-years mom had managed the household checking account. She was rather proud of the fact that she had never bounced a check and never been late paying a bill. This was the first sign that she was experiencing serious changes in memory and cognition. That day while arranging to have the power turned back on, my father set the electric account up for automatic payment.

Paying the Bills

Writing checks and paying the bills requires remembering to do so, doing so on time, making decisions about what bills to pay, what amounts to pay and even if to pay. As memory and cognition change doing this can be a real challenge. Setting up recurring bills on automatic payment will increase the likelihood that needed expenses are paid. Our clients may need not just our advice to set up automatic payment, but assistance with making the needed arrangements.

Automatic payment requires some oversight. There are three issues that need to be monitored; that all expected bills are received by the bank for payment, that the bills are paid by the bank in a timely manner and that the bills are correct. A simple way of doing this is a simple budget check list of monthly and other periodic expenses (such as insurance premiums) that someone checks a couple of times per month to assure that all bills are received and paid. Someone needs to review the charges. Unusual fluctuations in utility bills may be a sign of a billing error, or of something gone wrong at the residence. Unexpected charges on credit cards should be investigated. Oversight can be done by checking accounts online. Modern banking makes it very easy to set up online access to review accounts.

Keeping the Person Involved in Finances

Under the Person centered approach of SDM, even with direct deposit and automatic bill payments, it is still important to keep the Person informed and involved in their finances. For a long time into the progression of dementia, the Person will be able to check finances themselves and by using check lists on expected income and expenses they can spot irregularities and ask their trusted advisors for help. The advisors should also have access to the accounts and should double check to assure that all income is received, all expenses are normal in amounts and paid on time. As dementia progresses the advisors should always try to involve the Person in reviewing finances. It can be a formal sit down to review the accounts, or as simple as telling the Person your pension check was deposited and your water bill was paid out of your account. Keeping the Person informed about their finances will prolong their ability to

understand their finances. How you do this, will vary with the nature of the Person's illness and personal style.

Spending Money

It is important that Person with dementia continue to have access to spending money as long as they want it. As adults we normally have a limited amount of cash to spend as we please. For many of us, this is money no one asks us to account for. Think about it. Can you account for every dollar you have spent in the past 3-days? Probably not. Why do we ask adults with dementia to account for every dollar and in many cases refuse to give them spending money if they are unable to account for it. The amount should be something the Person can afford. One client of mine gave her father a roll of one-dollar bills each week. He felt rich with a thick bankroll, and in reality it was only a few dollars per week.

My grandfather had dementia when I was a teenager. I was helping my grandmother one morning, and he came into the kitchen, looked at my grandmother and said, "it is Friday" and held his hand out. She went into the bedroom and came back and handed him \$50 in cash. He went off to the bedroom, and I asked her "why did you give him money, he can barely find his way to the mailbox and back." She said, "It is Friday, for 50 years I have given him his allowance on Friday, if he remembers to ask I give it to him, it makes him feel like a whole person, and makes me feel good that he remembered this week. We can afford it, I don't care what he does with the money, in 50 years I never asked what he did with his pocket money, why should I ask now?"

Some guidance on spending money. Make sure the amount is affordable. Give it in cash. Don't expect or demand an accounting for it. Give it to them every few days. As long as the Person with dementia can do so encourage them to spend it on whatever they want. As we progress to credit cards being the norm, arrange credit cards or debit cards with low limits in accordance with what can be afforded.

Legally Empowering the Advisors

Selecting advisors is a crucial step in supported decision making. As dementia progresses the amount of help the advisors will need to provide in guiding and carrying out decisions will increase. At some point health care providers will become unwilling to accept consent for medical care from a Person with dementia. As a Person's dementia progresses, transacting business will become difficult and eventually impossible without assistance. Especially with significant transactions, businesses will become uncomfortable with transacting business with a

Person with dementia and will decline to do so. At these tipping points in the progression of dementia it is critical for the advisors to be legally empowered to carry out the wishes of the Person. Without legal empowerment, the advisors may find themselves unable to assist the Person in carrying out the wishes and choices of the individual.

Legally Empowering Advisors on Money

It is critically important that income be received and deposited and that bills and expenses be paid. While a lot of this can be set up to happen without anyone needing to do anything, not everything can. It is important that someone have the ongoing legal authority to receive income and spend it. Selecting the Person to advise and assist with money is critically important. The advisor / agent needs to work within the SDM model and consult with the Person, offer advice and guidance, and as necessary assure that the choice is carried out. Without legal authority, the advisor will sooner or later find themselves unable to carry out the wishes of the Person. Because of the progressive nature of dementia, the Person will sooner or later lose the ability to carry out wishes without help. Hence the advisor on money needs to be legally empowered.

Joint Accounts

Having a second or third name on a bank account is probably the most common way of empowering the advisor on money. Most couples have joint bank accounts, many older adults are encouraged to add the name of an adult child or other family member to their bank account. Joint accounts require some caution. Almost universally, the banks treat these accounts as joint accounts. Meaning that any Person whose name is on the account can withdraw all of the assets at any time. The joint account holder is presumed to be able to spend the account assets without restrictions, and the account can become subject to attachment, assignment or garnishment for debts of any joint account holder. It is legally possible to add an authorized signer on a bank account, but most banks make the Person a joint account owner. Joint accounts are also in a form that commonly creates a right of inheritance or right of survivorship. This can undermine the estate plan of the Person.

Bob was renewing a certificate of deposit at his bank one day. He remarked that when he died he wanted his daughter to receive the money in the account. The bank added her name as a joint account owner creating the right of inheritance he desired. What Bob didn't know was his daughter was on the verge of bankruptcy. He spent months hiring attorneys to defend his savings from his daughter's creditors.

With joint accounts careful selection and training of the joint account holder is essential to minimize the risk. First, a Person should only allow access to finances to another Person if they 100% trust them. If there is a shadow of a doubt, or the proposed joint account holder is high risk, don't do it. Risk factors include personal financial distress, health issues, mental health issues, drug or alcohol abuse or dependency. The Person being added needs to be instructed that the money in the account is not theirs, that it should only be used for the needs of the true owner, to keep and share with others full and complete records of all transactions, and if there is a change in their financial situation that might make them at risk of collections, to take their name off of the account. Theft or misuse of the account funds are all too common to not exercise great caution in adding names to accounts.

Power of Attorney

A power of attorney is a legal document appointing a Person to act as agent for the creator or grantor of the power. A power of attorney is an essential document for legally empowering the advisor or agent for money of a Person who is developing dementia. The authority granted in a power of attorney is what is described in the document or as allowed by state law.^{viii} A power of attorney empowers the advisory to transact business on behalf of the Person with dementia. It is essential that the power meet the requirements to be classified as durable under the laws of the state that it is created in.^{ix} Some states have specific signing formalities for the document to be valid.^x The execution requirements vary from merely signed, to signed, dated, witnessed and notarized.^{xi} The belt and suspenders approach of signed and dated in the presence of two impartial witnesses and a notary will provide the greatest likelihood of the document not being challenged based on how it is signed. When drafting powers of attorney, always keep in mind that the Person may own property, do business, or move to another state. Drafting and executing documents to the strictest standards is a best practice.

Just as selection of a joint account holder is critical, so is selection of the agent in a power of attorney. Powers of attorney can become a license to steal in the hands of the wrong Person. Though the agent is technically a fiduciary in virtually all jurisdictions, the liability for misuse most often falls to the agent, not third parties who have honored the document. Recovery of money stolen using a power of attorney, is difficult and often fails.

Powers of attorney should be drafted with great care

The powers included should only be those that the grantor wishes to grant after discussing what powers may or may not be necessary. Many attorneys always include gifting powers in a power of attorney, without careful consultation about the wishes of the grantor, or review the appropriateness of gifting to the Person's circumstances. Higher net worth clients are much more likely to benefit from gifting for asset planning or tax planning, than clients of modest means. Gifting powers for clients of modest means is all too often used to exploit the Person. For the majority of older Americans their home is their largest single asset, and an in depth

discussion should be had about if and when they would want their agent to be able to sell their home and an appropriate but restricted authority, if any, be included in the power of attorney. A third area of concern for clients of modest means is changing beneficiaries on life insurance policies. The life insurance benefit may be the greatest legacy of an older Person, while it may be necessary to assign it to pre-pay funeral arrangements for a Person applying for Medicaid benefits, a plenary power to change beneficiaries empowers the agent to significantly undermine the estate planning of the Person with dementia.

One of the advantages of SMD and powers of attorney is avoiding judicial interference and oversight, and at the same time the lack of oversight or monitoring is one of the risks of powers of attorney and SDM. Oversight and accountability can and should be drafted into a power of attorney. A power of attorney is essentially a contractual agreement between the grantor and agent, the terms of this can be what the parties agree to. At a minimum the agent should be required by the terms of the power of attorney to keep detailed records of who the agent has provided copies of the power of attorney to, of all transactions done using the document and of all financial or property records the agent has relating to the Person and the power of attorney. The agent should be contractually obligated to provide copies of all of these records to a named third party.

Additional contractual provisions between the grantor and agent common in SDM are useful when working with Persons with dementia.^{xii} The grantor can agree to consult with the agent and other advisors on all transactions above a threshold, to not revoke or terminate the power of attorney without consultation with advisors and an agreed cooling off period. These agreements set the tone for potential disagreements between the grantor and agent. One major goal should be to avoid a misunderstanding or miscommunication between the Person with declining memory and the well-meaning agent, resulting in the Person revoking the power and having no legally empowered advisor as their dementia progresses.

Health Care Decision Making and SDM

No right is more fundamental than making choices about what happens to one's body.^{xiii} While health care decisions range from simple decisions about routine exams and treatment to life and death decisions about end of life health care; the goal of health care should always be to provide the care that a Person wants.^{xiv} Few people make health care decisions without advice and guidance from others. When we see our doctors, the doctor is serving the SDM role of advisor or supporter. When we are referred for tests, to specialists, and for a second opinion, the medical professionals involved are all serving in the role of advisor and supporter. Ultimately the decision of what treatment to provide or not provide, is, or should be, based on the values, beliefs, goals and choices of the individual. With generous exceptions like emergency treatment, health care providers who treat without consent can be liable for damages for unauthorized and unwanted care. With the exception of deciding not to seek care or treatment at all, we make few health care decisions without trusted advisors. All health care is really supported decision making.

Virtually every Person will sooner later experience, at least a brief period of time, when they need help making and or communicating health care choices. For Persons with dementia, this need may stretch over a decade or more.^{xv} Outside of emergency situations Doctors shouldn't make health care decisions for patients.^{xvi} When the health care providers believe that the patient lacks the ability to make or communicate independent health care decisions, the providers turn to someone; family, friends, an ethics committee or consultant, to help make health care decisions. This process is ideally suited for application of SDM principles.

Persons with significant memory or cognitive impairments are still able to express in meaningful ways their likes and dislikes on health care treatment and should always be consulted. I recently witnessed a discussion about a feeding tube in the hospital room of a patient with mid to late stage dementia. The patient was not consulted, but spoke up saying, "no tubes, take me home." The most coherent sentence the patient had put together in days. Even a Person who can't clearly communicate may still be able to smile or grimace, one SDM conversant caregiver said, "when she spits the pills out, I know she does not want to take them."

Because health care is such a personal issue, encouraging every adult to select advisors to provide consent when the health care providers will no longer accept consent from the patient, is essential. The Person to help with health care decisions should be as familiar as possible with the Person's values, wishes, beliefs and health care goals.^{xvii} The advisor needs to be willing and able to help make difficult decisions, to listen to conflicting advice, to always involve the Person in making choices, even if all that can be done is to explain what is happening and why, and be strong enough to hear criticism of the choices that are made. Being a health care agent may possibly be the most challenging role for an advisor. The Person should have a role in selecting the advisor. In planning for decline in memory and cognition it is essential that the named health care advisor be legally empowered to act.

Legally Empowering Health Care Agents

The Supreme Court of the United States in Cruzan recognized the right of adults to have someone make health care decisions for them when they are unable to consent.^{xviii} Currently 44 states have statutes that give guidance in selecting someone to make health care decisions for a Person who is unable to give consent.^{xix} The Person preferred under the statute may not be the Person chosen or preferred by the Person. The most effective way to overcome the statutory preference is to name a Person to make health care decisions in writing. The legal requirements for designating a Person to consent to health care decisions varies at least slightly from state to state, with 5 states having unique requirements.^{xx} The Person legally empowered to make health care decisions may be called an agent, health care agent, attorney in fact, health care proxy, surrogate or representative.^{xxi} The appointment can be done in a variety of forms, a designation of health care surrogate, health care power of attorney, or a living will form that includes naming a surrogate.^{xxii} The most universal is a durable power of attorney that includes authority to make health care decisions. The appointment of a health care decision maker needs to be done in accordance with state law and in the state the Person is in

at the time the document is created.^{xxiii} Some states specifically prohibit certain Persons from serving as the health care decision makers, most generally health care providers, or anyone who might benefit from or be responsible as a third party for paying for the health care being provided.^{xxiv} There are specific signing formalities regarding qualified witnesses and notaries.^{xxv} Most state requirements are met with two neutral witnesses and a notary.^{xxvi} A handful of states have specific language that must be included for the form to be valid or fully effective.^{xxvii} The value of working with an attorney to appoint a health care decision maker, is assuring that the appointment is legally enforceable.

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ⁱⁱ Supported Decision Making: Protecting Rights, Ensuring Choices, Jonathan G. Martinis, BIFOCAL, Vol. 36, No. 5, May – June 2015, pages 107-110.

ⁱⁱⁱ <http://supporteddecisionmaking.org/>

^{iv} Brainstorming Guide: How Are We Already Using Supported Decision-Making?
<http://supporteddecisionmaking.org/sites/default/files/sdm-brainstorming-guide.pdf>

^v Supported Decision-Making: What, Why, & How, Morgan K. Whitlatch,
http://supporteddecisionmaking.org/sites/default/files/event_files/MD-Arc-2016-Convention.pdf

^{vi} **Early Diagnosis of Dementia**, Karen S. Santacruz, Daniel Swagerty, American Academy of Family Physicians, 2001, viewed online http://www.drplace.com/Early_Diagnosis_of_Dementia.16.26479.htm (7/22/2016)

^{vii} <https://www.ssa.gov/deposit/>

^{viii} POWER OF ATTORNEY LAWS: CITATIONS, BY STATE (Laws current as of 12/31/07), ABA Commission on Law and Aging,
http://www.americanbar.org/content/dam/aba/migrated/aging/about/pdfs/power_of_attorney_laws_citations_by_state.authcheckdam.pdf

^{ix} US Legal .com, <http://powerofattorney.uslegal.com/state-laws/>

^x Durable Powers of Attorney for Finances Compiled by Christine Jensen, William Mitchell College of Law '13,
https://nlrc.acl.gov/Legal_Issues/Advance_Directives/docs/50StateSurvey_POA.pdf

^{xi} Id.

^{xii} See generally Supported Decision Making, <http://supporteddecisionmaking.org/node/390>

^{xiii} See generally: Cruzan by Cruzan v. Director, Missouri Department of Health, 497 U.S. 261, (1990.)

^{xiv} A Right to Person-Centered Care Planning, Gwen Orłowski, Julie Carter, Justice in Aging, Issue Brief, April 2015.

^{xv} The later stages of dementia, Alzheimer's Society,

https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=101

^{xvi} • Coppola, Kristen M., et al., "Accuracy of Primary Care and Hospital-Based Physicians' Predictions of Elderly Outpatients' Treatment Preferences With and Without Advance Directives," Arch. Intern. Med. 161: 431-440 (2001)

^{xvii} See The Conversation Project <http://theconversationproject.org/>

^{xviii} Cruzan by Cruzan v. Director, Missouri Department of Health, 497 U.S. 261, (1990.)

^{xix} DEFAULT SURROGATE CONSENT STATUTES as of June 2014, compiled by the ABA Commission on Law and Aging, http://www.americanbar.org/content/dam/aba/administrative/law_aging/2014_default_surrogate_consent_statutes.authcheckdam.pdf

^{xx} Giving Someone a Power of Attorney for Your Healthcare (multi-state guide and form), ABA Commission on Law and Aging, http://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/power_atty_guide_and_form_2011.html

^{xxi} Substitute Decision-Maker Terminology Under State Law, ABA Commission on Law and Aging, 2016, http://www.americanbar.org/content/dam/aba/administrative/law_aging/SubstituteDecision-MakingTerminology.authcheckdam.pdf

^{xxii} State-Specific Advance Planning forms, ABA Commission on Law and Aging, http://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/Stateforms.html

^{xxiii} STATE HEALTH CARE POWER OF ATTORNEY STATUTES Selected Characteristics, January 2013, ABA Commission on Law and Aging, http://www.americanbar.org/content/dam/aba/administrative/law_aging/2013_HCPA-CHT-Jan_25_with_oral_directive_edits.authcheckdam.pdf

^{xxiv} ^{xxiv} id.

^{xxv} id.

^{xxvi} id

^{xxvii} Giving Someone a Power of Attorney for Your Healthcare (multi-state guide and form), ABA Commission on Law and Aging, http://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/power_atty_guide_and_form_2011.html