Decision Support for Adults Living with Chronic Kidney Disease
Disclaimer

These guidelines are not binding on nurses or the organizations that employ them. The use of these guidelines should be flexible based on individual needs and local circumstances. They neither constitute a liability nor discharge from liability. While every effort has been made to ensure the accuracy of the contents at the time of publication, neither the authors nor the Registered Nurses’ Association of Ontario (RNAO) give any guarantee as to the accuracy of the information contained in them nor accept any liability, with respect to loss, damage, injury or expense arising from any such errors or omission in the contents of this work.

This Program is funded by the Ontario Ministry of Health and Long-Term Care.

Copyright

With the exception of those portions of this document for which a specific prohibition or limitation against copying appears, the balance of this document may be produced, reproduced and published in its entirety without modification in any form, including in electronic form, for educational or non-commercial purposes. Should any adaptation of the material be required for any reason, RNAO written permission must be obtained. Appropriate credit or citation must appear on all copied materials as follows:


Contact Information

Registered Nurses’ Association of Ontario
International Affairs and Best Practice Guidelines Program
158 Pearl Street, Toronto, Ontario M5H 1L3

Website: www.rnao.org/bestpractices
Greetings from Doris Grinspun,
Executive Director Registered Nurses’ Association of Ontario

It is with great excitement that the Registered Nurses’ Association of Ontario (RNAO) presents this guideline, Decision Support for Adults Living with Chronic Kidney Disease, to the health care community. Evidence-based practice supports the excellence in service that nurses are committed to delivering in our day-to-day practice. RNAO is delighted to provide this key resource to you.

RNAO offers its heartfelt thanks to the many individuals and institutions that are making our vision for Nursing Best Practice Guidelines (BPGs) a reality: the Government of Ontario for recognizing our ability to lead the program and providing multi-year funding; Irmajean Bajnok, Director, RNAO International Affairs and Best Practice Guidelines (IABPG) Programs, for her expertise and leadership in advancing the production of the BPGs; each and every Team Leader involved, and for this BPG in particular —Gillian Brunier and Mary Ann Murray — for their superb stewardship, commitment and, above all, exquisite expertise. Also thanks to Jenny Oey Chung and Rishma Nazarali, RNAO’s IABPG Program Managers, for their intense work to see that this BPG moved from concept to reality. A special thanks to the BPG Panel — we respect and value your expertise and volunteer work. To all, we could not have done this without you!

The nursing community, with its commitment and passion for excellence in nursing care, is providing the knowledge and countless hours essential to the development, implementaton, evaluation and revision of each guideline. Employers have responded enthusiastically by nominating best practice champions, implementation and evaluating the guidelines and working towards a culture of evidence-based practice.

Successful uptake of these guidelines requires a concerted effort from nurse clinicians and their health care colleagues from other disciplines, from nurse educators in academic and practice settings and from employers. After lodging these guidelines into their minds and hearts, knowledgeable and skillful nurses and nursing students need healthy and supportive work environments to help bring these guidelines to practice actions.

We ask that you share this guideline with members of the interdisciplinary team as there is much to learn from one another. Together, we can ensure that the public receives the best possible care every time they come in contact with us. Let’s make them the real winners in this important effort!

Doris Grinspun, RN, MScN, PhD(c), O. ONT.
Executive Director
Registered Nurses’ Association of Ontario
# Table of Contents

## Background

- How to Use this Document ............................................................... 6
- Purpose and Scope ........................................................................ 7
- Summary of Recommendations ..................................................... 8
- Interpretation of Evidence ............................................................... 9
- Development Panel ....................................................................... 10
- Stakeholder Acknowledgement ...................................................... 12
- Key Assumptions .......................................................................... 14
- Background Context for Chronic Kidney Disease ......................... 15
- Background Information for Shared Decision Making and Patient Decision Support ................................................................. 21
- Theoretical Framework .................................................................. 22
- Recommendations Mapped onto the Ottawa Decision Support Framework ................................................................. 23

## Recommendations

- Practice Recommendations .............................................................. 24
- Education Recommendations .......................................................... 38
- Organization & Policy Recommendations ....................................... 40
- Research Gaps and Future Implications .......................................... 44
- Process for Review and Update of the Guideline ............................... 45
How to Use this Document

This nursing best practice guideline is a comprehensive document providing resources necessary for the support of evidence based nursing practice. The document needs to be reviewed and applied, based on the specific needs of the organization or practice setting/environment, as well as the needs and wishes of the client. Guidelines should not be applied in a “cookbook” fashion but used as a tool to assist in decision making for individualized client care, as well as ensuring that appropriate structures and supports are in place to provide the best possible care.

Nurses, other health care professionals and administrators who are leading and facilitating practice changes will find this document valuable for the development of policies, procedures, protocols, educational programs, assessment and documentation tools, etc. It is recommended that the nursing best practice guidelines be used as a resource tool. Nurses providing direct client care will benefit from reviewing the recommendations, the evidence in support of the recommendations and the process that was used to develop the guidelines. However, it is highly recommended that practice settings/environments adapt these guidelines in formats that would be user-friendly for daily use. This guideline has some suggested formats for such local adaptation and tailoring.

Organizations wishing to use the guideline may decide to do so in a number of ways:

a) Assess current nursing and health care practices using the recommendations in the guideline.

b) Identify recommendations that will address identified needs or gaps in services.

c) Systematically develop a plan to implement the recommendations using associated tools and resources.

The RNAO is interested in hearing how you have implemented this guideline. Please contact us to share your story. Implementation resources will be made available through the RNAO website to assist individuals and organizations to implement best practice guidelines.
Purpose and Scope

Self-management and decision support are recognized as integral components of many models for chronic disease prevention and management (Improving Chronic Illness Care, 2005; World Health Organization, 2002). Canadians generally wish to participate in decisions about their health (O’Connor et al., 2002, 2003) and patients and families want providers to listen to their views and preferences (Coulter, 2005). As well, professional standards of practice and guidelines call for patient inclusion in care planning (College of Nurses of Ontario [CNO], 2006a; RNAO, 2006). Decision support is part of the informed consent process (Government of Ontario, 1996). Therefore, the guideline development panel chose to focus this guideline on increasing the capacity of nurses to support patients in making the numerous decisions required for optimum health promotion and disease management across the trajectory of chronic kidney disease (CKD). The patient is defined as an individual age 18 or older diagnosed with CKD.

The purpose of this best practice guideline is:

- To help nurses recognize patients with CKD experiencing decisional conflict related to situations in which there is more than one option available for managing their condition.
- To help nurses support patient involvement in reaching quality health decisions. Quality decisions are made using the best available evidence about the options and are consistent with the patients’ values.

Clinical questions addressed in the guideline include:

1. What are the common health decisions faced by patients with CKD?
2. How can nurses involve patients in making decisions about the monitoring and management of CKD?
3. What interventions support involvement of patients with CKD in making these decisions?
4. How can nurses evaluate the quality of the decision-making process, including the decision support provided to patients with CKD?
5. How can organizations facilitate and monitor the provision of decision support?

This guideline contains recommendations and tools for nurses (Registered Nurses, Registered Practical Nurses, Advanced Practice Nurses, etc.) caring for patients with CKD, and working in various practice settings. Implications for clinical practice, administration and education are discussed.
## Summary of Recommendations

### Practice Recommendations

<table>
<thead>
<tr>
<th>RECOMMENDATION</th>
<th>Type of Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Decision-Making Needs</td>
<td></td>
</tr>
<tr>
<td>1.0 Nurses know the common decisions faced by an adult with Chronic Kidney Disease (CKD).</td>
<td>Ia</td>
</tr>
<tr>
<td><strong>Nursing Actions:</strong></td>
<td></td>
</tr>
<tr>
<td>■ Nurses identify the decision the patient is facing at a particular point in time</td>
<td></td>
</tr>
<tr>
<td>2.0 Nurses screen the patient for decisional conflict at initial contact and as the patient’s situation and condition changes.</td>
<td>IV</td>
</tr>
<tr>
<td><strong>Nursing Actions:</strong></td>
<td></td>
</tr>
<tr>
<td>■ Nurses screen for decisional conflict</td>
<td></td>
</tr>
<tr>
<td>3.0 Nurses determine the source of patient’s decisional conflict.</td>
<td>III</td>
</tr>
<tr>
<td><strong>Nursing Actions:</strong></td>
<td></td>
</tr>
<tr>
<td>■ Nurses assess the patient’s knowledge and expectations about the options</td>
<td></td>
</tr>
<tr>
<td>■ Nurses assess and discuss the availability of resources</td>
<td></td>
</tr>
<tr>
<td>■ Nurses objectively measure the patient’s confidence and ability for making decisions and self-managing their CKD</td>
<td></td>
</tr>
<tr>
<td>■ Nurses assist the patient to clarify his/her values</td>
<td></td>
</tr>
<tr>
<td>■ Nurses clarify the patient’s preferred role in decision making and who else the patient wants to involve in the decision-making process</td>
<td></td>
</tr>
<tr>
<td>Decision Support Interventions</td>
<td></td>
</tr>
<tr>
<td>4.0 Nurses understand the difference between providing patient education and decision support.</td>
<td>IV</td>
</tr>
<tr>
<td><strong>Nursing Actions:</strong></td>
<td></td>
</tr>
<tr>
<td>■ Nurses describe patient education</td>
<td></td>
</tr>
<tr>
<td>■ Nurses describe the additional elements involved with decision support</td>
<td></td>
</tr>
<tr>
<td>5.0 Nurses use patient decision aids and other tools to provide decision support.</td>
<td>Ia</td>
</tr>
<tr>
<td><strong>Nursing Actions:</strong></td>
<td></td>
</tr>
<tr>
<td>■ Nurses remain neutral when supporting the patient in the decision-making process</td>
<td></td>
</tr>
<tr>
<td>■ Nurse use validated tools to provide decision support</td>
<td></td>
</tr>
<tr>
<td>■ Nurses help the patient to build confidence in participation in decision making</td>
<td></td>
</tr>
<tr>
<td>■ Nurses meet the patient’s knowledge needs</td>
<td></td>
</tr>
<tr>
<td>■ Nurses help the patient clarify his/her values</td>
<td></td>
</tr>
<tr>
<td>■ Nurses help the patient to identify and mobilize resources</td>
<td></td>
</tr>
<tr>
<td>■ Nurses help the patient to communicate with others during the decision-making process</td>
<td></td>
</tr>
<tr>
<td>■ Nurses obtain commitment from the patient for the next decision-making step(s)</td>
<td></td>
</tr>
</tbody>
</table>
**Education Recommendation**

<table>
<thead>
<tr>
<th>RECOMMENDATION</th>
<th>Type of Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.0 Programs focusing on pre-licensure nursing education, workplace orientation, clinical mentorship and continuing professional development include content about evidence-informed patient decision support.</td>
<td>Ia</td>
</tr>
<tr>
<td><strong>Nursing Education Strategies:</strong></td>
<td></td>
</tr>
<tr>
<td>■ Decision support concepts</td>
<td></td>
</tr>
<tr>
<td>■ Application of concepts</td>
<td></td>
</tr>
<tr>
<td>■ Seminar courses</td>
<td></td>
</tr>
<tr>
<td>■ Clinical mentorship</td>
<td></td>
</tr>
<tr>
<td>■ Case studies</td>
<td></td>
</tr>
<tr>
<td>■ Scenario-based interactions</td>
<td></td>
</tr>
<tr>
<td>■ Teaching about practice theories</td>
<td></td>
</tr>
</tbody>
</table>

**Organization & Policy Recommendations**

<table>
<thead>
<tr>
<th>RECOMMENDATION</th>
<th>Type of Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>7.0 Health care organizations provide financial, material and human resources for nurses to guide the adult with Chronic Kidney Disease to make quality decisions.</td>
<td>III</td>
</tr>
<tr>
<td>8.0 Organizations and regional health authorities develop and monitor key indicators of evidence-based patient decision support.</td>
<td>III</td>
</tr>
</tbody>
</table>

**Interpretation of Evidence**

**Types of Evidence**

The evidence to guide decision support for patients with CKD and the recommendations outlined in this best practice guideline (BPG) are reported according to the type of evidence as outlined below.

Ia  Evidence obtained from meta-analysis or systematic review of randomized controlled trials.
Ib  Evidence obtained from at least one randomized controlled trial.
IIa Evidence obtained from at least one well-designed controlled study without randomization.
IIb Evidence obtained from at least one other type of well-designed quasi-experimental study, without randomization.
III Evidence obtained from well-designed non-experimental descriptive studies, such as comparative studies, correlation studies and case studies.
IV  Evidence obtained from expert committee reports or opinions and/or clinical experiences of respected authorities.
### Development Panel Members

<table>
<thead>
<tr>
<th>Gillian Brunier, RN(EC), MScN, CNeph(C)</th>
<th>Lee Ann Craig, RN, MScN, CDE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Co-Team Leader</strong></td>
<td></td>
</tr>
<tr>
<td>Nurse Practitioner, Nephrology</td>
<td>Advanced Practice Nurse</td>
</tr>
<tr>
<td>Sunnybrook Health Sciences Centre</td>
<td>London Health Sciences Centre</td>
</tr>
<tr>
<td>Toronto, Ontario</td>
<td>London, Ontario</td>
</tr>
<tr>
<td><strong>Mary Ann Murray, RN, MScN, PhD, CON(C), GNC(C), CHPCN(C)</strong></td>
<td><strong>Sylvie Leung, RN, MN, CNeph(C), CNN, CCTN</strong></td>
</tr>
<tr>
<td><strong>Co-Team Leader</strong></td>
<td></td>
</tr>
<tr>
<td>University of Ottawa</td>
<td>PhD Student</td>
</tr>
<tr>
<td>Ottawa, Ontario</td>
<td>Faculty of Nursing</td>
</tr>
<tr>
<td></td>
<td>University of Alberta</td>
</tr>
<tr>
<td><strong>Debra Appleton, RN, MN, CNeph(C)</strong></td>
<td><strong>Cynthia Mills, RN, BN, CNeph(C)</strong></td>
</tr>
<tr>
<td>Clinical Educator</td>
<td>Professional Practice Leader/Cl</td>
</tr>
<tr>
<td>University Health Network</td>
<td>Clinical Educator</td>
</tr>
<tr>
<td>Toronto General Hospital</td>
<td>Hotel Dieu Grace Hospital</td>
</tr>
<tr>
<td>Toronto, Ontario</td>
<td>Windsor, Ontario</td>
</tr>
<tr>
<td><strong>Margaret Avery, RD, BSc</strong></td>
<td><strong>Eleanor Ravenscroft, RN, MSN, PhD, CNeph(C)</strong></td>
</tr>
<tr>
<td>Renal Dietitian</td>
<td>Patient Care Manager, Renal Unit</td>
</tr>
<tr>
<td>Peterborough Regional Health Centre</td>
<td>Sunnybrook Health Sciences Centre</td>
</tr>
<tr>
<td>Peterborough, Ontario</td>
<td>Toronto, Ontario</td>
</tr>
<tr>
<td><strong>Janet Baker, RN, BN, CNeph(C)</strong></td>
<td><strong>Jane Ridley, RN(EC), MScN, CNeph(C)</strong></td>
</tr>
<tr>
<td>Clinician, Kidney Function Clinic</td>
<td>Nurse Practitioner</td>
</tr>
<tr>
<td>Halton Healthcare Services</td>
<td>London Health Sciences Centre</td>
</tr>
<tr>
<td>Oakville, Ontario</td>
<td>London, Ontario</td>
</tr>
<tr>
<td><strong>Janice Bissonnette, RN(EC), MScN, PhD(C)</strong></td>
<td><strong>Dawn Stacey, RN, MScN, PhD, CON(C)</strong></td>
</tr>
<tr>
<td>Nurse Practitioner/Manager</td>
<td>Assistant Professor</td>
</tr>
<tr>
<td>The Renal Transplant Program</td>
<td>University of Ottawa</td>
</tr>
<tr>
<td>The Ottawa Hospital</td>
<td>Ottawa, Ontario</td>
</tr>
<tr>
<td>Ottawa, Ontario</td>
<td><strong>Alison Thomas, RN, MN, CNeph(C)</strong></td>
</tr>
<tr>
<td><strong>Alison Thomas, RN, MN, CNeph(C)</strong></td>
<td>Nurse Practitioner</td>
</tr>
<tr>
<td><strong>Co-Team Leader</strong></td>
<td>St. Michael’s Hospital</td>
</tr>
<tr>
<td><strong>University Health Network</strong></td>
<td>Toronto, Ontario</td>
</tr>
<tr>
<td><strong>Toronto General Hospital</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Toronto, Ontario</strong></td>
<td></td>
</tr>
</tbody>
</table>
Elizabeth Ton, RN, BN
Nursing Student
UNB-Humber Collaborative BN Program
Toronto, Ontario

Mary Wrigley, RN, HBScN, CNeph(C)
Coordinator, Chronic Kidney Disease, Transplant
Thunder Bay Regional Health Sciences Centre
Thunder Bay, Ontario

Julie Burris
Program Assistant
Registered Nurses’ Association of Ontario
Toronto, Ontario

Jenny Oey Chung, RN, BScN, MN
Program Manager
Registered Nurses’ Association of Ontario
Toronto, Ontario

Rishma Nazarali, RN, BScN, MN
Program Manager
Registered Nurses’ Association of Ontario
Toronto, Ontario

The RNAO would also like to acknowledge
Dawn Kingston, RN, MSc, PhD(student)
Research Assistant
for her contribution to the systematic review.

All members of the development panel are volunteers.
Declarations of interest and confidentiality have been
made. Further details are available from the Registered
Nurses’ Association of Ontario.
Stakeholder Acknowledgement

Stakeholders representing diverse perspectives were solicited for their feedback and the Registered Nurses’ Association of Ontario wishes to acknowledge the following for their contribution in reviewing this Nursing Best Practice Guideline:

<table>
<thead>
<tr>
<th>NAME, CREDENTIALS</th>
<th>TITLE, ORGANIZATION, CITY, PROVINCE</th>
</tr>
</thead>
<tbody>
<tr>
<td>RAJNEET ATKAR, RN, BN, CNEPH(C)</td>
<td>Clinical Nurse Educator, Alberta Health Services, Calgary, Alberta</td>
</tr>
<tr>
<td>SANDRA BARTLETT, RN, BED(C)</td>
<td>Nurse Case Manager, London Health Sciences Centre, London, Ontario</td>
</tr>
<tr>
<td>FATIMA BENJAMIN-WONG, RN</td>
<td>Clinical Coordinator, Humber River Regional Hospital, Toronto, Ontario</td>
</tr>
<tr>
<td>JANET BICK</td>
<td>Director, Policy &amp; Programs, The Kidney Foundation of Canada, Toronto, Ontario</td>
</tr>
<tr>
<td>M. ANNE BRINKMAN, BSW, RSW</td>
<td>Program Manager, The Kidney Foundation of Canada, Windsor, Ontario</td>
</tr>
<tr>
<td>PAULINE CERNIGOJ</td>
<td>Renal Patient, Thunder Bay, Ontario</td>
</tr>
<tr>
<td>ANGELIQUE CHAI, RN, BScN, MN, CNEPH(C)</td>
<td>Registered Nurse, Lakeridge Health, Oshawa, Ontario</td>
</tr>
<tr>
<td>LUCIA COSTANTINI, RN, MN</td>
<td>Registered Nurse, Credit Valley Hospital, Mississauga, Ontario</td>
</tr>
<tr>
<td>VANESSA DECK, RN, CNEPH(C)</td>
<td>Patient Care Manager, Halton Healthcare Services, Oakville Ontario</td>
</tr>
<tr>
<td>CATHERINE DOMINSKI, RN, CNEPH(C)</td>
<td>Registered Nurse, Regional Hemodialysis Centre, London Health Sciences Centre, London, Ontario</td>
</tr>
<tr>
<td>JUDITH ELLIS, RN, BScN</td>
<td>Director, Renal Program, Hotel Dieu Grace Hospital, Windsor, Ontario</td>
</tr>
<tr>
<td>VALERIE FISET, RN, MScN</td>
<td>Professor, Nursing Studies, Algonquin College, Ottawa, Ontario</td>
</tr>
<tr>
<td>ALEXIS HANDKE, RN, CNEPH(C)</td>
<td>Ward Nurse, Dialysis Unit, Ottawa Hospital Civic Campus, Arnprior, Ontario</td>
</tr>
<tr>
<td>EMILY HARRISON, RN, BHScn, CNEPH(C)</td>
<td>Renal Chronic Disease Prevention and Management Project Leader, Lakeridge Health, Oshawa, Ontario</td>
</tr>
<tr>
<td>LORI HARWOOD, RN, MSc, CNEPH(C)</td>
<td>Advanced Practice Nurse, London Health Sciences Centre, London, Ontario</td>
</tr>
<tr>
<td>DEBBIE HODGINS, BA, BSW, RSW</td>
<td>Social Worker, Hotel Dieu Grace Hospital, Windsor, Ontario</td>
</tr>
<tr>
<td>STACEY E. HOLLOWAY, BSW, RSW</td>
<td>Medical Social Worker, Renal Program, Halton Healthcare Services, Oakville, Ontario</td>
</tr>
</tbody>
</table>
To gain a better understanding of the patients’/families’ preferred role in decision making the Registered Nurses’ Association of Ontario wishes to acknowledge the following for their contribution in reviewing this Nursing Best Practice Guideline:

Focus Group Participants

DORIS CHUDOVA  
Focus Group Participant, Etobicoke, Ontario

RUKHSANA FAZIL  
Focus Group Participant, Oakville, Ontario

ERNIE FENNIMORE  
Focus Group Participant, Milton, Ontario

LESLEY FENNIMORE  
Focus Group Participant, Milton, Ontario

NOREEN HURREN  
Focus Group Participant, Campbellville, Ontario

RUSSEL HURREN  
Focus Group Participant, Campbellville, Ontario

RON NEWMAN  
Focus Group Participant, Oakville, Ontario

DAVE RACINSKY  
Focus Group Participant, Mississauga, Ontario

BILL WHITAKER  
Focus Group Participant, Oakville, Ontario

JUDY WHITAKER  
Focus Group Participant, Oakville, Ontario

Key Assumptions

The recommendations within this guideline were written with the following key assumptions in mind:

1. Patient involvement is important in how decisions are made in the management of CKD.
2. Within the context of CKD, each patient’s experience is unique, and requires a holistic assessment and individualized interventions.
3. Patient’s need for support with decision making is variable and should be individually tailored.
4. Patient’s desire to be involved in decision making may evolve over time.
5. Monitoring and treatment options depend on individual patient’s circumstances, availability of resources and health care funding.
6. This BPG is not prescriptive; rather, it is intended to promote the provision of highest quality decision support for adults with CKD.
7. Nurses are one of several health care provider groups that are involved in supporting patient involvement in decision making.
Background Context for Chronic Kidney Disease

Chronic Kidney Disease

Chronic kidney disease (CKD) is defined as kidney damage or a glomerular filtration rate of < 60ml/min/1.73m² for three or more months, irrespective of cause (Canadian Society of Nephrology [CSN], 2007; Levey et al., 2003). CKD is a slow, insidious process occurring over years and possibly decades. It is a silent disease in which 50 to 75% of the nephrons may be damaged or lost before overt symptoms of renal failure occur (Porter, 1999).

CKD Diagnosis, Monitoring and Staging

Though serum creatinine levels may be used to assess kidney function, when used alone they are an inaccurate marker. Kidney function is normally calculated by glomerular filtration rate; there are variations in how different labs report this rate. The Canadian Society of Nephrology recommends the reporting of an estimated glomerular filtration rate (eGFR). The eGFR is a calculation used to estimate the volume of fluid the kidneys filter based on a standard body mass index. Just as hypertension is not diagnosed with one reading, diagnosis of CKD is based on serial measurements of kidney function as opposed to one eGFR calculation (CSN, 2007).

CKD is divided into five stages (see Table 1). The diagnosis of CKD may not occur until later stages as the signs and symptoms of the disease are not immediately evident. Screening individuals at risk for CKD may result in earlier diagnosis. Not all individuals will progress through to stage five, as the goal of treatment is to prevent progression of the disease.
### Table 1: Stages of CKD (Adapted from Kidney Foundation of Canada, 2008; Levin, 2003)

<table>
<thead>
<tr>
<th>STAGE</th>
<th>DESCRIPTION</th>
<th>KIDNEY FUNCTION</th>
<th>MANIFESTATIONS+ REMAINING</th>
<th>CALCULATED/ESTIMATED GLOMERULAR FilTRATION RATE (eGFR)*</th>
<th>ACTION**</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Kidney damage with normal or increased eGFR</td>
<td>Few symptoms experienced</td>
<td>&gt; 90</td>
<td>Diagnosis and treatment of co-morbid conditions, slowing progression, CVD*** risk reduction</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Kidney damage with mildly decreased eGFR</td>
<td>Some changes to laboratory values (e.g. serum urea and creatinine)</td>
<td>60-90</td>
<td>Estimating progression</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Moderately decreased eGFR</td>
<td>Symptoms may be experienced</td>
<td>30-60</td>
<td>Evaluating and treating complications</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Severely decreased eGFR</td>
<td>Increase in laboratory value abnormalities</td>
<td>15-30</td>
<td>Preparation for kidney replacement therapy</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Kidney Failure Often referred to as ESRD</td>
<td>Decisions required around treatment options</td>
<td>&lt; 15</td>
<td>Replacement (if uremia present)</td>
<td></td>
</tr>
</tbody>
</table>

+The table is intended to be a guide; manifestations of CKD will vary among individuals.
*eGFR may be calculated by some laboratories, reported differently according to institution/setting, or may not be reported at all. Serum creatinine and a calculated eGFR together provide a better indication of kidney function. The Calculated/Estimated Glomerular Filtration Rate is reported in ml/min/1.73m².
**Includes actions from preceding stages
***Cardiovascular disease
Incidence, Causes and Risk Factors

An estimated 2 million Canadians have kidney disease or are at risk for it. It is difficult to determine the exact incidence of CKD, as it is often only diagnosed in later stages. The incidence of individuals requiring renal replacement therapy (RRT) is more accurately documented; between 1997 and 2006, the rate of incident RRT in Canada rose 32%. As of December 31, 2006, 33,832 Canadians were registered as having end-stage renal disease (ESRD). Of those, 20,465 (hemodialysis [HD] and peritoneal dialysis [PD]) were on dialysis and 13,367 had functioning renal transplants (CIHI, 2008).

Leading causes of CKD include diabetes (34.4%), vascular disease (19.5%), unknown cause (12.9%) and glomerulonephritis (11.6%) (CIHI, 2008). However, the causes of CKD are not always clear, as there are numerous risk factors and etiologies. Table 2 states risk factors for CKD along with examples.

Table 2: Risk Factors for CKD (Adapted from Levey et al., 2003)

<table>
<thead>
<tr>
<th>RISK FACTOR</th>
<th>DEFINITION</th>
<th>EXAMPLES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Susceptibility</td>
<td>Increase susceptibility to kidney damage</td>
<td>Older age; family history of CKD; culture/ethnicity (e.g. First Nations); low income or education</td>
</tr>
<tr>
<td>Factors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Initiation Factors</td>
<td>Directly initiate kidney damage</td>
<td>Diabetes; high blood pressure; autoimmune diseases; systemic infections; urinary tract infections; urinary stones; lower urinary tract obstruction; drug toxicity</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Progression Factors</td>
<td>Cause worsening kidney damage and faster decline in kidney function after the initiation of kidney damage</td>
<td>Higher level of proteinuria; higher blood pressure; poor glycemic control; smoking</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>End-stage Factors</td>
<td>Increase morbidity and mortality in kidney failure</td>
<td>Inadequate dialysis; anemia; low serum albumin; late nephrology referral</td>
</tr>
</tbody>
</table>

CKD is not just a disease of the kidneys. The cardiovascular, neurological, endocrine, hematological, respiratory, musculoskeletal and integumentary systems are among the body systems impacted. In particular, CKD is a marker for increased burden of cardiovascular disease. The risk of cardiovascular disease increases two-fold in early CKD and accounts for approximately half of all deaths in patients on dialysis (Collins, 2003).
Terminology

Many terms are used interchangeably with CKD. The most common are chronic renal insufficiency (CRI), progressive renal insufficiency (PRI) and end-stage renal disease (ESRD). The use of multiple terms is confusing for both practitioners and patients. For example, the term ESRD can be applied in several ways: some use the term interchangeably with CKD, while others consider it to be Stage 5 CKD (see Table 1). In the United States (US), ESRD is used to refer to individuals on dialysis or having received a transplant, regardless of the “stage” of their kidney disease (Levey et al., 2002).

The Kidney Foundation of Canada (KFoC), the Canadian Society of Nephrology (CSN), the National Kidney Foundation (NKF), and the Canadian Association of Nephrology Nurses and Technologists (CANNT) use the term chronic kidney disease (CKD). In keeping with this practice, CKD is therefore used throughout this guideline.

Continuum of Care

CKD is a progressive disease that may be viewed along a continuum. At present, there is no cure. CKD management focuses on early detection and treatment that may delay or slow the rate of progression and reduce the incidence of adverse health outcomes. One of the goals in the treatment of CKD is to provide patients with the education and support needed in order to encourage active participation in their care. The RNAO Best Practice Guideline Self-Management Support (in development at the time this document was produced) is applicable and of value to the CKD population, as patients will likely be engaged in varying degrees of self-care.

The CKD continuum extends from the point of diagnosis to end-of-life care. Health care for individuals with CKD involves screening, diagnosis, treatment and support of self-care management for both CKD and co-morbid illness. While early detection and treatment may slow the progression of CKD, unfortunately, the disease may progress in many individuals and treatment plans must be discussed with patients and family members. The treatment options for End-Stage Renal Disease (ESRD) include renal transplant, peritoneal dialysis (PD), hemodialysis (HD) and conservative management. A summary of treatment options is found in Table 3 and Figure 1.
Table 3: Treatment Options

1. Renal transplant
   - A healthy kidney from a living or deceased donor is transplanted into the recipient.
   - Both recipient and donor have a rigorous work-up prior to the transplant to ensure suitability.
   - Requires daily immunosuppressive medications (which have associated adverse effects) to prevent rejection.
   - Rejection can occur at any time.

2. Peritoneal dialysis
   - The peritoneal membrane is used to remove waste products and excess water from the circulation with the aid of commercially prepared dialysis solutions administered through a surgically implanted peritoneal dialysis catheter.
   - Most often done as a home therapy; can be performed in most environments.
   - Can be done manually numerous times throughout the day; or at night, while sleeping via the assistance of a machine; or in some cases both.
   - Flexible daily therapy facilitates a more normalized diet and lifestyle.

3. Hemodialysis
   - A hemodialyzer is used to remove waste products and excess water from the circulation with the aid of a hemodialysis machine.
   - A fistula/graft created surgically is the preferred route of access to the bloodstream. A central venous catheter may also be used.
   - Provided in a dialysis facility or at home with varying frequency e.g. daily, nocturnal or intermittent modalities.
   - Diet and fluid restrictions continue for most patients on this type of dialysis.

4. Conservative management/Palliative care
   - A patient or family may decide to forego or to discontinue renal replacement therapy (RRT) with the intention of accepting death as a natural outcome.

5. Trial of dialysis
   - A trial of dialysis with a finite time frame may be undertaken when a patient is unsure of the benefit that RRT will provide.
   - The patient/family, as well as members of the Nephrology team, should participate in the discussion at the end of the trial period about the next steps in the continuum of care.

6. Episodic review
   - Review of treatment modality should be undertaken at any time if the burden of treatment outweighs the benefit to the patient. This should be communicated to the patient during the initial phase of decision coaching and education.
BACKGROUND

* All options may not be appropriate for all individuals

Individuals diagnosed with CKD need to come to terms with a disease process that has an unpredictable and variable trajectory. There is a great deal to learn about the disease and its management. See Appendix D for management regimes and lifestyle changes associated with CKD. Individual reactions to the diagnosis can be as varied as the individuals afflicted. People are often overwhelmed by the diagnosis and the decisions they are quickly confronted with. The intent of this guideline is to provide nurses with guidance on assisting and supporting individuals in making decisions about managing their CKD.
Background Information for Shared Decision Making and Patient Decision Support

Patient participation in health care decision making is often called shared decision making. Patients who have been involved in decisions about their health and health care may experience:
- increased satisfaction with their decision
- increased quality of life
- higher levels of psychological functioning
- increased sense of well-being
- delayed disease progression, and decreased morbidity and mortality
- decreased levels of anxiety and depression
- increased feelings of control over their illness
- increased self-efficacy

(King, 1998, 2000; Marron et al., 2005)

When decision making is shared, practitioners (e.g. nurses, physicians, social workers) and patients decide together on the best option. Practitioners provide information about the health related reasonable options, benefits and risks. Patients bring information about what is most important and practical for them in their situation. The aim is to make a decision that is informed by the best available scientific evidence and consistent with patients’ views on what is most important to them.

Multiple options are often available for treating or managing CKD, each option having different benefits and risks. Patients facing these ‘tough decisions’ may feel uncertain about which option to choose or what next steps to take. This is called decisional conflict (O’Conner, 1995).

Decisional conflict is defined as a state of uncertainty about a course of action that occurs when two or more clinically reasonable options have benefits and harms that an individual patient may value differently (NANDA, 2005).

Decisional conflict occurs when patients feel unable to make quality decisions regarding their care (Lin, Lee & Hicks, 2005). A patient’s ability to make these decisions may be hampered by:
- not having enough information
- being uncertain about what to expect
- being unclear about what is most important
- feeling pressured or unsupported
- impaired cognition related to physiological disease processes and/or emotional stress

Other factors that may affect a patient’s ability to make a choice include:
- interruptions in self-identity and self-concepts
- fear of suffering
- fear of loss of lifestyle
- fear of death
- fear of becoming a burden
- worry over perceived physical limitations (Andrew, 2001)
Decision support provides a means to understanding what may be contributing to the patient’s decisional conflict. Decision support can then be tailored to address sources of patient’s decisional conflict. Involving patients in shared decision making can help to ensure that patients get the care that meets their needs and that best fits their preferences, energy and situation.

Every day, patients make decisions about their lifestyle and how to manage their condition. Patients often require information about the link between their lifestyle and CKD-related treatment decisions. Meeting patients’ information needs is an important part of helping patients to plan and manage their self-care. Appendix D outlines examples of treatment and lifestyle regimens that are associated with the management of CKD.

Additional educational resources for patients and health care providers can be found in Appendix H.

**Theoretical Frameworks**

Based on a review of several decision support conceptual models (see Appendix I), the Ottawa Decision Support Framework was considered to be the most congruent with the purpose of this best practice guideline (O’Connor et al., 1998). This framework was used to guide the literature review, guideline structure and clinical examples presented.

According to the Ottawa Decision Support Framework, decision support involves three key steps:

a) assessing patients’ level of decisional conflict and related decision-making needs
   (e.g. knowledge, values clarity, resources and confidence for making and implementing the decision)

b) providing support to help minimize patients’ decision-making needs by:
   - providing tailored information on options, benefits and harms
   - clarifying values associated with outcomes of options
   - helping patients manage pressure and/or conflicting views of others
   - enhancing self-help skills in making and implementing decisions

c) evaluating the quality of the patient’s decision and the decision-making process

Decision making is influenced by characteristics of the patient and practitioner including age, gender, culture and preferred roles in decision making.

The main assumption underlying the Ottawa Decision Support Framework (ODSF) is “the selection of one alternative over another depends not only on the client and practitioner characteristics but also on whether they [patients] are knowledgeable about the issues, expect the alternative will likely lead to outcomes they most value; are reasonably certain this is the best alternative; perceive it important others agree with and are supportive of the alternative; and have the necessary personal and external resources to make and implement the choice” (O’Connor et al., 1998, p.268).

The ODSF has been used to organize and structure the recommendations included in this guideline.
Recommendations Mapped onto the Ottawa Decision Support Framework (O’Connor et al., 1998)

**Patient Decision-Making Needs (clinical question 1)**

**Recommendation 1.0:** Nurses know the common decisions faced by an adult with CKD.

**Recommendation 2.0:** Nurses screen the patient for decisional conflict at initial contact and as the patient’s situation and condition changes.

**Recommendation 3.0:** Nurses determine the source of patient’s decisional conflict.

**Decision Support Interventions (clinical questions 2, 3)**

**Recommendation 4.0:** Nurses understand the difference between providing patient education and decision support.

**Recommendation 5.0:** Nurses use patient decision aids and other tools to provide decision support.

**Broader Education, Organization and Policy Level Recommendations (clinical questions 3, 5)**

**Recommendation 6.0:** Programs focusing on pre-licensure nursing education, workplace orientation, clinical mentorship and continuing professional development include content about evidence-informed patient decision support.

**Recommendation 7.0:** Health care organizations provide financial, material and human resources for nurses to guide the adult with Chronic Kidney Disease to make quality decisions.

**Recommendation 8.0:** Organizations and regional health authorities develop and monitor key indicators of evidence-based patient decision support.
Practice Recommendations:

Patient Decision-Making Needs

RECOMMENDATION 1
Nurses know the common decisions faced by an adult with Chronic Kidney Disease (CKD).
Type of Evidence: Ia

Discussion of Evidence:

Patients face decisions about the management of their condition at different points during the course of their illness. Many patients will also have other co-existing chronic and/or acute health conditions that will compound the number and type of decisions; for example, many patients also have diabetes mellitus and/or cardiovascular disease (CIHI, 2008).

There are many health care related decisions that most adults with CKD will face as a consequence of having this chronic condition. Some decisions may need to be made regardless of the stage of the patient’s CKD; other decisions may only be faced by patients at more advanced stages of CKD. For instance, all adults with CKD are likely to face decisions about managing lifestyle factors that may influence their health outcomes. In contrast, only adults with progressive CKD in whom kidney failure is expected may need to make decisions about renal replacement therapy (RRT). A general awareness of the typical decisions faced by adults with CKD will assist nurses to identify specific decisions that a particular patient may be facing (see Appendix D).

A systematic review undertaken by Murray et al. (in press) reviewed 30 studies describing decisions faced by patients with CKD. Of those studies, 22 were descriptive, six were qualitative, one was a randomized control trial and one was a narrative review. Type of RRT, withholding or withdrawing dialysis and renal transplant were the more frequently reported decisions. Less frequently reported decisions included scheduling of treatments, adherence to care plans, selection of vascular access devices and preferred level of participation in self-care (Murray et al., in press).

Nursing Actions:

- Nurses identify the decision the patient is facing at a particular point in time

To provide timely decision support, it is important to recognize specific decision(s) the patient is facing. Nurses may anticipate decisions given their knowledge of common decisions faced by patients with CKD. Alternatively, nurses may recognize that a patient is facing decisional conflict and verify the decision through discussion with the patient.

Common decisions include:
- Should I make changes to my diet or continue with my usual dietary patterns?
- Should I take my medications as prescribed?
- Should I have peritoneal dialysis or hemodialysis?
- Should I undergo a kidney transplant or not?
RECOMMENDATION 2:
Nurses screen the patient for decisional conflict at initial contact and as the patient’s situation and condition changes.

Type of Evidence: IV

Discussion of Evidence:

Decisional conflict is common. In a cross-sectional survey, 65% of Canadians surveyed reported that they had faced complex health decisions and 59% reported having experienced decisional conflict (O’Connor et al., 2003).

Nurses interact with patients across a wide range of populations, practice settings and sectors making them ideally situated to screen patients for decisional conflict. Valid and reliable tools to assess for decisional conflict include the Traditional Decisional Conflict Scale (see Appendix J), which is also available in French, Danish and Chinese, or the 4-item SURE version that is easy to use in everyday clinical practice (see Table 4).

Given the progressive nature of CKD and changes in patients’ personal circumstances, patients are likely to require ongoing screening for decisional conflict (O’Connor et al., 2003). While no CKD specific screening tools were identified in the systematic review (Murray et al., in press), valid and reliable tools non-specific to CKD are available.

The Ottawa Health Decision Centre (OHDC), within the Ottawa Health Research Institute, has developed a number of practical tools and resources that can help patients and families facing tough CKD related decisions. The group has also compiled an inventory of patient decision aids from around the world. In the inventory, the decision aids are quality rated using an internationally approved set of criteria. Information about these quality criteria can be found in the A to Z inventory of Patient Decision Aids at www.decisionaid.ohri.ca/index.html.

Nursing Actions:

- Nurses screen for decisional conflict

Nurses can use the SURE tool (see Table 4) to screen for decision conflict. The SURE tool identifies (a) uncertainty about a decision; and (b) modifiable factors influencing decisional conflict such as inadequate knowledge, unclear values and need for support and advice.

To screen for decisional conflict the nurse asks the patient each of the four questions in the SURE tool. The patient can respond with “Yes,” “No,” or “Unsure.” If a patient answers “Unsure” or “No” for any question, then further nursing assessment is required as described in Recommendations 3 to 5. At a minimum, nurses can screen for uncertainty by asking the first question only.
Table 4: SURE Tool
Copyright O’Connor and Légaré, 2006. Printed with permission.

<table>
<thead>
<tr>
<th>ACRONYM</th>
<th>ITEMS</th>
<th>RESPONSES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sure of myself...</td>
<td>Do you feel SURE about the best choice for you?</td>
<td>Yes  Unsure  No</td>
</tr>
<tr>
<td>Uninformed...</td>
<td>Do you know the benefits and risks of each option?</td>
<td>Yes  Unsure  No</td>
</tr>
<tr>
<td>Risk/Benefit ratio...</td>
<td>Are you clear about which benefits and risks matter most to you?</td>
<td>Yes  Unsure  No</td>
</tr>
<tr>
<td>Encourage...</td>
<td>Do you have enough support and advice to make a choice?</td>
<td>Yes  Unsure  No</td>
</tr>
</tbody>
</table>

RECOMMENDATION 3:
Nurses determine the source of patient’s decisional conflict.

Type of Evidence: III

Discussion of Evidence

When decisional conflict is identified, further assessment is necessary to determine the source of decisional conflict. Common sources of decisional conflict include inadequate knowledge of options, unclear values and feeling unsupported in the process of decision making (O’Connor, 1998).

For patients with CKD, most research has focused on information needs around treatment approaches. A systematic review of 34 primary studies and six reviews of factors influencing patient decision making in CKD reported that patients want information on: 1) general knowledge about kidney disease, treatment options and renal transplant; 2) lifestyle management; 3) self-care (e.g. dietary and fluid management, skin care); and 4) end-of-life planning (Murray et al., in press).

Particular factors that influence decision making in patients with CKD are summarized in Table 5. Furthermore, patients’ degree of decisional conflict may vary depending on the patients’ age, gender, education status, employment, severity of disease, personality, coping style, value placed on health and preferred role in decision making (Arora & McHorney, 2000; Elwyn et al., 2003; Horsburgh et al., 2000; Nease & Brooks, 1995; Orsino, 2003).
Table 5: Factors Influencing Patient Decision Making in CKD

<table>
<thead>
<tr>
<th>FACTORS INFLUENCING DECISIONS FOR CKD PATIENTS</th>
<th>EXAMPLE</th>
<th>SOURCE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interpersonal relationships</td>
<td>Opinions of others</td>
<td>Gordon, 2001</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Orsino, 2003</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Tweed &amp; Caesar, 2005</td>
</tr>
<tr>
<td></td>
<td>Knowing others’ experiences</td>
<td>Ashby et al., 2005</td>
</tr>
<tr>
<td></td>
<td>Interactions between providers and patient</td>
<td>Gordon, 2001</td>
</tr>
<tr>
<td></td>
<td>Self-perceived burden to family</td>
<td>Gordon, 2001</td>
</tr>
<tr>
<td></td>
<td>Trust in providers</td>
<td>Ashby et al., 2005</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Wuerth et al., 2002</td>
</tr>
<tr>
<td>Preservation of current well-being, normality and quality of life</td>
<td>Concerns about daily living</td>
<td>Tweed &amp; Caesar, 2005</td>
</tr>
<tr>
<td></td>
<td>Maintaining current lifestyle</td>
<td>Davison, 2006</td>
</tr>
<tr>
<td>Need for control</td>
<td>Wish for personal preferences to shape future</td>
<td>Gordon, 2001</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Wuerth et al., 2002</td>
</tr>
<tr>
<td></td>
<td>Managing the situation</td>
<td>Calvin, 2004</td>
</tr>
<tr>
<td></td>
<td>Maintaining individuality</td>
<td>Calvin, 2004</td>
</tr>
<tr>
<td></td>
<td>Being personally responsible</td>
<td>Ashby et al., 2005</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Lin et al., 2005</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Tweed &amp; Caesar, 2005</td>
</tr>
<tr>
<td>Personal weightings for benefit/risk ratios</td>
<td>Perceptions about outcomes and consequences of dialysis</td>
<td>Calvin, 2004</td>
</tr>
<tr>
<td></td>
<td>Willingness to take chances</td>
<td>Gordon, 2001</td>
</tr>
<tr>
<td></td>
<td>Fear if things don’t go well</td>
<td>Gordon, 2001</td>
</tr>
<tr>
<td></td>
<td>Potential for disappointment</td>
<td>Orsino, 2003</td>
</tr>
<tr>
<td>Information overload</td>
<td>Too much information gathered by searching the Internet, speaking to others and provided by health care professionals</td>
<td>Expert panel consensus</td>
</tr>
</tbody>
</table>

Nursing Actions:

To determine the source of decisional conflict, the nurse assesses decision making needs related to the patient:

- having adequate knowledge about options and their outcomes;
- being clear about his/her values associated with the outcomes of options being considered; and
- feeling pressured or unsupported in the decision-making process.
Nurses assess the patient’s knowledge and expectations about the options

When assessing the patient’s decision-making needs, it is helpful to determine what the patient already knows and needs to know in order to make an informed decision. Nurses can assess patient information needs with respect to (a) the natural course of the condition if untreated; (b) the options and procedures involved; (c) the potential benefits of each option; and (d) the potential side-effects of each option, including severity and likelihood of these side effects (Elwyn, 2006; Hurst, 2004; Tunzi, 2001).

To determine the patient’s understanding of the decision and options, nurses can invite the patient to share what he/she already knows and his/her expectations associated with different options. Nurses can then identify possible gaps in the patient’s knowledge and/or unrealistic expectations.

Examples of questions for exploring knowledge and expectations:

1. Assessing knowledge:
   a) Do patients understand the information received?
   b) Can patients describe the risks and benefits?
   c) Can patients reason, or make personal sense of the information in a way that allows an understanding of how the information applies to their individual circumstances?

2. Assessing expectations: (Arora & McHorney, 2000; Elwyn et al., 2003; Entwistle & Watt, 2006; Holmes-Rovner et al., 1996)
   a) Do patients have a realistic understanding about the nature of CKD and the impact on their health and personal circumstances?
   b) Do patients have realistic expectations about the benefit and side effects of options?
   a) Do patients have realistic expectations about how different choices can impact their personal circumstances?

Nurses assess and discuss the availability of resources

Nurses need to assess patient access to resources that can influence the decision (e.g. equipment, access to providers/informal care givers, time). Another issue for consideration is the environment in which the condition will be monitored and/or managed. For example, patients living in rural communities may have inadequate water pressure to support home hemodialysis and/or space to accommodate the supplies and equipment. Another example is that if dietary restrictions are necessary, a patient’s living arrangement may impede his/her access to recommended foods.

Examples of questions for exploring need for resources:
   a) Tell me about your living arrangements. Who do you live with?
   b) Do you need any help to take your medications? If so, who helps you?
   c) Who prepares your meals?
   d) How do you get to your appointments?
Nurses objectively measure the patient’s confidence and ability for making decisions and self-managing their CKD

Important in the patient taking an active role in decision making and managing his/her CKD is his/her level of confidence (or self-efficacy) with the activities required, ability to learn new skills, and usual coping style (Arora & McHorney, 2000; Elwyn et al, 2003; Entwistle & Watt, 2006; Hurst, 2004; Murray et al., in press). Bandura (1997) proposed that self-efficacy, often referred to as confidence, is a key prerequisite for behaviour change and is an important aspect of disease self-management (Bodenheimer et al., 2002). The strength of an individual’s conviction about his/her ability to produce a specific outcome determines whether or not he/she will attempt to deal with a difficult situation. Previous experiences with making health decisions and self-care also influence one’s confidence and abilities. Past experience for the kidney transplant patient includes previous dialysis routines, dialysis access formation and wait for donation. In a retrospective comparison of patients with late acute kidney transplant rejection (LAR) and medication taking behaviour, Baines (2002) found a significant relationship (p < .05) between negative physical and psychological states, lower levels of self-efficacy, poorer medication taking behaviour and episodes of LAR. Denhaerynck (2007) found renal transplant patients with lower levels of self-efficacy, as measured by the long-term medication behaviour self-efficacy scale, had a higher incidence of self-reported difficulty with medication self-management.

Nurses need to determine how confident patients are in their ability to make decisions and self-manage their disease successfully on an ongoing basis. Knowing a patient’s degree of confidence provides the nurse with guidance on where best to focus strategies to enhance confidence and the likelihood of successful self-management behaviour. The use of three-point response scales provides a simple and objective method of assessing a patient’s level of confidence (Risser, Jacobson & Kripalani, 2007). A decision self-efficacy scale can be used to measure a patient’s perceived self-confidence about engaging in shared decision making. An example of a decision self-efficacy scale is available at: http://decisionaid.ohri.ca/docs/develop/Tools/Decision_SelfEfficacy.pdf.

Other examples of questions that can be used to assess the patient’s confidence related to various CKD decisions are highlighted in the box below.

Examples of questions for assessing patients’ level of confidence using response options:

\((1 = \text{not confident} \quad 2 = \text{somewhat confident} \quad 3 = \text{very confident})\)

a) How confident are you that your decision for renal replacement therapy type is the right one for you?

b) How confident are you that you can attend all your dialysis appointments?

c) How confident are you that you can take your medications correctly?

d) How confident are you that you can take your medications correctly when they cause some side effects?

Nurses assist the patient to clarify his/her values

Previous studies indicate that practitioners tend to focus on providing information. Less attention is given to meeting patients’ other decision-making needs, such as helping patients to be clear about what they consider to be the most important consequences of the options under consideration to achieve or avoid (Elwyn, 2005; Guimond et al., 2003; Stacey, 2005). Training in decision support has been shown to increase nurses’ skill in focusing on patients’ values and support needs (Stacey, 2008).
Preferences for options are strongly influenced by patients’ values. It is important to assess patients’ values associated with procedures and potential outcomes of the different options. An easy way to assess a patient’s values associated with options is to assess the personal importance of the patient’s values in relation to the features of the options being considered. For example, some patients may rate “living with someone who has donated a kidney to them” as something to avoid. Another patient may feel it is more important to receive a kidney from a known relative in order to shorten the wait time for transplantation.

Specific questions for assessing values:

a) What are your fears, concerns or doubts related to the options you are considering?
b) What is your goal in managing your CKD?
c) What do you want to avoid in this decision?
d) What is really important for you to achieve in this decision?

Further examples of how to help patients clarify their values are described in Recommendation 5.0.

- **Nurses clarify the patient’s preferred role in decision making and who else the patient wants to involve in the decision making process**

There may be individual variation among patients for participation in decision making. Therefore, nurses need to assess these preferences when decisions are being made. A systematic review found that when patients are initially diagnosed with a new health problem, they have lower expressed preferences for involvement in health decisions but with decision support, they are more likely to take an active role in decision making (O’Connor, 2007). As well, evidence is beginning to emerge to show that individuals who were actively involved in deciding about their treatment had better health outcomes. For example, while no studies specific to CKD have been reported, one study found that women actively involved in decisions about their breast cancer treatment were more satisfied with the care they received and had improved quality of life, higher physical and social functioning and fewer reported side effects (Hack, 2006).

Nurses can assess patient’s preferences for participation in decision making using the adapted Control Preferences Scale (Degner, 1997):

<table>
<thead>
<tr>
<th>When decisions need to be made about your health, how much do you usually like to be involved?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Make the decision on your own</td>
</tr>
<tr>
<td>Share responsibility for making the decision with your doctor and/or others (specify ________________________)</td>
</tr>
<tr>
<td>Have someone else make the decision for you (specify ________________________)</td>
</tr>
</tbody>
</table>

Others who may be involved in making the decision depend on the clinical circumstances, patient preferences and decision(s) being made. In addition, patients’ cognitive capacity may impact their ability to participate. Patients may feel pressured or unsupported in decision making. For example, a patient may feel pressured to use traditional, alternative therapies, based upon cultural beliefs and values and the opinions of community elders and family members, rather than to continue dialysis or opt for supportive end-of-life care.
Specific questions to assess involvement of others include:
   a) Who has provided you with their opinion of this situation?
   b) Whose opinion is important to you?
   c) Do you feel supported by their opinion?
   d) Do you feel pressure to choose a specific option?

Practice Recommendations:
Decision Support Interventions

RECOMMENDATION 4:
Nurses understand the difference between providing patient education and decision support.
Type of Evidence: IV

Discussion of Evidence:

Many renal programs offer individual and group education to patients and their families. Usually, the goal is to provide patients with the information needed to understand their illness and be involved in their care. While education is vital for managing CKD, education alone is not adequate to support patient involvement in making decisions about the management of CKD. For instance, guidelines for conducting family conferences confirm the need to address decision making in order to clarify and set goals for future care (Hudson et al., 2008).

Health care providers are not always comfortable or equipped to recognize and address patients’ decisional conflict and other decision-making needs (Elwyn et al., 1999; Godolphin et al., 2001; Guimond et al., 2003; Legare et al., 2006; Makoul et al., 1995; Murray, Burns, See Tai, Lai & Nazareth, 2004; Stacey et al., 2005).

Patient education focuses on information provision. The goal is to improve patients’ knowledge. In patient education situations, nurses elicit a patient’s information needs by assessing their health literacy, knowledge, opinions, expectations and experiences pertaining to a particular health concern (Sahlsten, 2008). Then, patient education is adapted to meet the identified information needs (Eldh, 2006; Sainio, 2003; Tutton, 2005).

Decision support is necessary when there is more than one reasonable option, including the option to continue with the current plan of care. It focuses on information provision plus exploring patients’ values about what aspects of the options are most important to them. As well, decision support involves identifying other individuals influencing the decision (e.g., family, friends and health care providers) and resources needed to make or implement the decision. The goal is to help patients make higher quality decisions, defined as informed by the best available evidence and consistent with patients’ values.

There is strong evidence from multiple systematic reviews that standard patient education approaches are inadequate when helping patients make decisions (Coulter & Ellins, 2007; O’Connor et al., 2008).
Table 6: Comparison of Elements in Patient Education and Decision Support
(+ = included; – = not typically included)

<table>
<thead>
<tr>
<th>APPROACH</th>
<th>OPTIONS &amp; OUTCOMES</th>
<th>INFORMATION ABOUT CLINICAL PROBLEM</th>
<th>OUTCOME PROBABILITIES</th>
<th>EXPERIENCE OF OTHERS</th>
<th>EXPLICIT VALUES CLARIFICATION</th>
<th>ROLE OF OTHERS IN DECISION MAKING</th>
<th>GUIDANCE IN STEPS OF DECISION MAKING</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Education</td>
<td>–</td>
<td>+</td>
<td>–</td>
<td>+/–</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Decision Support</td>
<td>+</td>
<td>+</td>
<td>+/–</td>
<td>+/–</td>
<td>+</td>
<td>+/-</td>
<td>+/-</td>
</tr>
</tbody>
</table>

(Adapted from Coulter & Ellins, 2007; O’Connor, 2007; Winterbottom, 2007)

**Nursing Actions:**

- **Nurses describe patient education**

Nurses are able to describe patient education that is focused on helping patients learn about the disease and ways it can be managed. See Appendix D for management regimes and lifestyle changes associated with CKD.

- **Nurses describe the additional elements involved with decision support**

Nurses know that decision support is intended to improve the patient’s knowledge about options, clarity of values associated with options and feeling supported in the process of decision making.

**RECOMMENDATION 5.0**

Nurses use patient decision aids and other tools to provide decision support.

Type of Evidence: Ia

**Discussion of Evidence:**

Important in providing decision support is ensuring that the care is individualized to patients’ needs (Costantini et al., 2008; Coulter & Ellins, 2007). To individualize care, interventions need to be selected based on the assessed needs of patients as discussed in Recommendation 3.0.

Decision support interventions need to address modifiable factors causing decisional conflict and help prepare patients to participate in decision making in ways they prefer. Strong evidence from systematic reviews (Type 1a) and randomized control trials (Type 1b) indicate that there are several effective strategies for engaging patients to participate in decision making. These include well-designed information materials combined with decision-support tools, patient decision aids, and personalized consultation with health care professionals (Coulter & Ellins, 2007; O’Connor et al., 2007; O’Connor et al., 1999).

Decision Support interventions can be tailored to a patient’s desired level of involvement in decision making.
making and the intensity of decision-support needs. Helping patients participate may require a variety of
approaches, such as including close family members and friends in discussions, providing opportunities
for patients to consult with community elders, individual counselling, pre-visit information outlining
decision support strategies, tailored decision coaching and use of decision aids. It is important to revisit
decisions periodically, as circumstances and preferences may change over time.

Nursing Actions:

- **Nurses remain neutral when supporting patients in the decision-making process**

Nurses need to be aware that they may influence decisions made by patients by what they say and what
they do. Nurses need to avoid biasing the decision-making process. They should be aware of their per-
sonal opinions and ensure that their own beliefs and preferred solutions do not influence the decision-
making process.

For more information, please see the RNAO BPG Establishing Therapeutic Relationships (2002; Revised
2006), and the College of Nurses of Ontario Therapeutic Nurse-Client Relationship Practice Standard
(Revised 2006).

Examples of questions nurses can ask themselves to ensure they are not biasing
the decision-making process:

- Am I presenting the information in a balanced manner?
- Am I presenting both positive and negative aspects of the options under consideration?
- Am I presenting my personal opinion?
- Am I pressuring the patient to decide on a particular option?

- **Nurses use validated tools to provide decision support**

Patient decision aids can compliment decision support counselling. Decision aids generally include
evidence-based information about options, probabilities of benefits and risks, values clarification and
assessment of other opinions regarding the decision. Patient decision aids come in a variety of formats
such as workbooks, audiotapes, decision boards, interactive videos and web based applications.

Decision support approaches/tools should include the following elements outlined by the International

- Information about options and the potential benefits, harms and side effects of each option.
- Information about the probability of experiencing benefits, harms and side effects related
to options discussed.
- Information about the specificity and sensitivity of screening or diagnostic procedures.
- Values clarification exercises.
- Assessment of resources and the role of others in decision making.
- Identification of next steps.
Patient Decision Aid Resources:

A-Z Inventory of Decision Aids (http://decisionaid.ohri.ca/AZinvent.php)
- contains up-to-date and available decision aids identified by the Cochrane Systematic Review Group that meet established quality criteria

The Ottawa Personal Decision Guide (OPDG) (http://decisionaid.ohri.ca/decguide.html)
- designed for any health-related and/or social decision
- two-page, self-administered format can be printed and completed by hand
- one-page format can be filled in online and printed

Nurses help the patient to build confidence in participation in decision making

Nurses can build patient confidence in participating in decision making through positive reinforcement.

Strategies to build patient confidence in participating in decision making:
- Use the decision coaching model (see Appendix K).
- Provide counseling in deliberating about the steps of decision making (knowing options; benefits and risks of potential outcomes; being clear about values; being clear about others’ role in decision-making process and feeling supported in decision making).
- Walk through the decision with the patient using a decision aid.
- Help the patient to practice sharing informed values with others through role play and problem solving scenarios.

Nurses meet the patient’s knowledge needs

Knowledge needs can be met by helping the patient to access relevant information about the options available and the potential outcomes of the options. All options, including the option of not making a change, need to be presented. Potential benefits and harms should both be presented, as well as information about continuing with the current course of action.

People often overestimate their risk of experiencing a rare side effect; therefore, information needs to be presented in a balanced manner. The chances of experiencing particular outcomes need to be presented in balanced ways. In cases when patients over or underestimate the chances of an outcome occurring, the nurse can acknowledge the possibility, as well as describe situations where the outcome did not happen and other situations where the outcome did happen.

Information can be provided verbally, or as written, web based or multimedia materials. Prior to providing information materials to patients, nurses need to critically review the information for accuracy, completeness, readability and plain language. For example, a large scale evaluation in the United Kingdom (UK) of patient information leaflets regarding RRT found that most leaflets were difficult to understand, rarely included information about risks or treatment limitations and did not include techniques to facilitate patient involvement in decision making (Winterbottom, 2007). Finally, nurses need to assess the patient’s comprehension of the information provided.
Specific steps in meeting knowledge needs:
1. Present all available options, including not making a change.
2. Present examples of others’ choices to help the patient understand there is no one best answer.
3. Provide statistics on variation in choice: e.g., how many people choose the different options that are available; differences in practitioners’ opinions; or differences in practice guidelines.
4. Provide rationale that underlies the differing opinions. Differences in choices can reflect scientific uncertainty, differences in people’s circumstances, tolerance for risk or uncertainty or their values.
5. Confirm patient’s understanding of information presented.
6. Give a balanced presentation of information; that is, not favouring one option over another.
7. Use a variety of educational methods to engage patient in learning (e.g., patient/patient or nurse/patient) and materials (e.g. written, visual, audio, etc.).
8. Base information on up-to-date, accurate evidence.
9. Present information in plain language to increase patient understanding.
10. Present probabilities to patient clearly using both words and numbers.
11. Tailor information.
12. Brainstorm with patient and answer questions.
13. Check patient understanding of information provided.
14. Assist patient to ask questions and raise concerns.

Nurses help the patient clarify his/her values

Patients may feel unclear about what is most important to achieve or avoid around the options being considered. As well, others, including family, friends and clinicians, are not very good at predicting or knowing what patients consider to be most important. Values clarification exercises can help the patient to weigh the potential benefits and risks against what is most important to him/herself personally (Bruera et al., 2001).

Ways to clarify values:
1. Help the patient understand how an outcome will personally affect him/her.
   For example: describe time needed for hemodialysis in terms of impact on daily activities, feeling pressured by other time commitments and not being able to participate in some valued activities.
2. Ask patient to rate the personal importance of the positive and negative outcomes he/she is considering using a number scale. (e.g., from 0 to 5, with 0 not important to avoid or achieve; 5 very important to avoid or achieve).
3. List the patient’s ratings of personal importance of options.
4. Ask the patient to think about which option has the reasons that are most important to him/her.
5. Based on the patient’s overall rating, ask the patient if he/she is now leaning towards a particular option or if he/she is still unsure.
6. Provide the patient with his/her personal values profile and summary statement to share with others involved in the decision.
Nurses help the patient to identify and mobilize resources

Nurses can help patients to identify and mobilize the resources needed for making and implementing decisions. These include personal resources such as the patient’s experience in decision making and their confidence in dealing with others’ opinions. Other resources include environmental (e.g., water, electricity), financial and community (e.g., homecare services and people important to the patient) resources. Nurses collaborate with other health care professionals to support the patient in the decision-making process.

Ways to mobilize resources:
- Clarify what resources the patient needs to make a decision:
  - More information,
  - Input from: personal advocates, family and friends.
- Facilitate a team conference or family meeting.
- Consult allied health team.

Nurses help the patient to communicate with others during the decision-making process

To support the patient in making decisions, nurses can help him/her clarify his/her perceptions of others’ opinions, share preferences and discuss strategies to deal with differing opinions.

Ways to facilitate patient communication with others:
- Confirm who else is involved in this decision.
- Establish their role in the decision:
  - Sharing the decision making with the patient;
  - Not part of making decision, but being aware of decision made by the patient;
  - Making the decision for the patient.
- Identify how this person can support the patient in his/her decision making.
- Identify what this person would need to support the patient in his/her decision making:
  - More information about the options and potential outcomes;
  - To understand the likelihood of potential benefits or risks to the patient;
  - To understand what is important to the patient;
  - To understand the personal implications of this decision to those close to the patient.

Strategies for dealing with people who are exerting pressure:
- Plan how to communicate information and values;
- Share informed values with others using values clarification exercise summaries;
- Invite others to share their perceptions to find areas of agreement and disagreement;
- Mobilize social support (e.g., other family members, close friends, community elders);
- Identify a mediator, if needed;
- Role play and rehearsal of communication strategies.
Nurses obtain commitment from the patient for the next decision-making step(s)

Nurses can obtain commitment from the patient for the next step(s) in making and implementing the decision.

Practical Questions to Confirm Next Steps
Ask the patient to confirm what he/she needs to do before making a choice:
1. Are you ready to make a plan?
2. Do you need to discuss the options with anyone else?
3. If so, with whom?_____________________________
4. Do you need to learn more about your options?
5. Do you need anything else to help you make your choice?
6. Will you be ready to make the decision by______________________?
7. If not, what is keeping you from making the decision?

In summary, decision support is aimed at helping patients to reach quality decisions that are informed by the best available evidence and consistent with patient values. Figure 2 summarizes the steps in helping patients make timely quality decisions.

Figure 2: Steps in Decision Support
Education Recommendation

**RECOMMENDATION 6**

Programs focusing on pre-licensure nursing education, workplace orientation, clinical mentorship and continuing professional development include content about evidence-informed patient decision support.

Type of Evidence: Ia

Discussion of Evidence:

The Canadian Nurses Association describes the “shared-care” model of responsibility and accountability for health and illness care. Under this model, nurses are increasingly expected to coordinate care, deliver direct services, help patients to understand their options and guide them to navigate the health system (Villeneuve, 2006). As health care workers with unique knowledge and skills, nurses engage in lifelong learning to be current with emerging knowledge and are competent to provide safe patient care (CNO, 2002, 2005, 2006b). Evidence-informed patient decision support is a relatively new nursing intervention that builds upon the role of patient educator. Currently, many practicing nurses have not been exposed to decision support. There are educational resources available to help nurses enhance their knowledge and skills about providing decision support. For example, decision support education can be provided through professional development activities, orientation programs, clinical mentorships and quality assurance initiatives.

Health professionals may be unaware of or misperceive patient preferences. Results of a systematic review (134 papers) on communication between patients and health professionals showed mixed findings about the extent to which patients felt that their beliefs, experiences and preferences could be shared (Stevenson, 2004). Other studies specific to nursing indicate that nurses often do not know their patients’ preferences (Leighl, 2001), and that nurses are generally unaware that differences in opinion exist (Kane, 1996). Gravel, Legare, & Graham (2006) conducted a systematic review (31 papers) of barriers and facilitators to implementing patient decision support in practice. It was evident that lack of both provider self-efficacy and familiarity with shared decision support make it more difficult to implement shared decision making. Researchers have also found that hospice nurses participating in a needs assessment identified patient decision support as a key learning need (Murray, Fiset, O’Connor, 2004).

Encouraging champions to promote new practices in the clinical setting has shown some promise in influencing uptake (Gifford, 2007). For instance, a systematic review (12 studies) has shown that local opinion leaders (champions) are effective in promoting evidence-based practice (Doumit, 2007).

There is evidence that interactive educational sessions on evidence-based decision support are effective in strengthening practitioners’ competence and confidence in providing decision support. For example, there is Type I b evidence to show that educational interventions that included the Ottawa Decision Support Tutorial, plus skill building workshops, improved nurses’ knowledge and skills in providing decision support (Stacey, O’Connor, Graham, & Pomey, 2006; Stacey, Steginga, Jacobsen, & Dunn, 2006). Compared to the control group, nurses who participated in the educational interventions were more likely to assess patients’ information needs, discuss values associated with their options and discuss support needs related to others involved in the decision. There was no increase in the length of time for these decision support
interactions. Another study, of 122 family physicians, revealed that exposure to a training workshop, feedback and point-in-time reminders influenced their intention to adopt shared decision making with patients (Legare, 2005). Furthermore, a systematic review (Type 1a evidence) of providers’ perceptions of barriers and facilitators to implementing decision support found that motivation and positive attitudes facilitated implementation and suggested that role models and champions may help to influence the uptake of patient decision-support practices (Gravel, Legare, & Graham, 2006).

Nursing Education Strategies

A number of education strategies can be used to help nurses develop and strengthen their patient decision support skills. Some examples follow:

- **Decision support concepts**
  - Introduction of decision support concepts in didactic courses

- **Application of concepts**
  - Application of concepts in course assignments appropriate to learner’s level of nursing knowledge (diploma, undergraduate, graduate)

- **Seminar courses**
  - Seminar courses contribute to continued development of skills and integration of experiences from clinical practicums

- **Clinical mentorship**
  - Clinical mentorship modeling patient decision support and facilitation of opportunities for students to participate in patient decision support interventions

- **Case studies**
  - Case studies can strengthen clinical problem-solving skills by improving understanding of how concepts and principles relate to patients’ condition and care (Azzarello, 2006)

- **Scenario-based interactions**
  - Scenario-based interactions with standardized patients in simulation laboratories may be useful in developing competencies. Practicing nurses returning to study at graduate levels and those preparing to practice in the extended class may find this approach especially helpful as simulation offers a safe environment to practice and refine new skills.

- **Teaching about practice theories**
  - Teaching about the Ottawa Decision Support Framework as a practice theory

Table 7 shows how nurses can move toward competence in providing decision support to patients living with CKD.
The Patient Decision Aids research group, Ottawa Health Research Institute (www.ohri.ca), has established an inventory of tools and resources to help patients and their health practitioners work through health related decisions (http://decisionaid.ohri.ca/index.html). Resources include an A–Z inventory of patient decision aids and an online auto-tutorial available to help practitioners develop skills in providing decision support.

The Ottawa Decision Support Tutorial (www.ohri.ca/decisionaid)
OHRI A to Z inventory of decision aids (http://decisionaid.ohri.ca/AZinvent.php)

### Table 7: Evolving Decision Support Competencies
(Adapted from Stacey et al., 2008)

<table>
<thead>
<tr>
<th>Exposure</th>
<th>Immersion</th>
</tr>
</thead>
<tbody>
<tr>
<td>■ aware of intra/interprofessional roles (scopes of practice) in decision support</td>
<td>■ participate in educational activities (e.g. tutorial, workshop, self-directed study, case-based discussions, conferences)</td>
</tr>
<tr>
<td>■ aware of decisional conflict and modifiable factors</td>
<td>■ provide decision coaching in role play and/or with simulated patient(s)</td>
</tr>
<tr>
<td>■ recognize personal attitudes toward patient involvement in decision making</td>
<td>■ obtain commitment to try decision coaching in practice</td>
</tr>
<tr>
<td>■ aware of decision support resources (e.g. RNAO BPG supplement Client Centred Care; Decision Support for Adults Living with CKD)</td>
<td>■ integrate decision coaching in clinical practice</td>
</tr>
<tr>
<td></td>
<td>■ participate in an intra/interprofessional approach to decision support</td>
</tr>
</tbody>
</table>

The Patient Decision Aids research group, Ottawa Health Research Institute (www.ohri.ca), has established an inventory of tools and resources to help patients and their health practitioners work through health related decisions (http://decisionaid.ohri.ca/index.html). Resources include an A–Z inventory of patient decision aids and an online auto-tutorial available to help practitioners develop skills in providing decision support.

### Organization & Policy Recommendations

#### RECOMMENDATION 7
Health care organizations provide financial, material and human resources for nurses to guide the adult with Chronic Kidney Disease to make quality decisions.

Type of Evidence: III

#### Discussion of Evidence:

Organizations and regional health authorities should consider patient decision support integral to quality nursing practice. Successful uptake of patient decision support interventions requires organizational support and the implementation of sustainable infrastructures. Time constraints have been identified by providers as a barrier to providing decision support (Gravel, 2006). However, nurses in a health call centre...
found no increase in their call time when using decision support interventions (Stacey, 2005). Embedding cues for patient decision support in care pathways and documentation systems would further facilitate time efficiencies and uptake of decision support interventions. In another meta-analysis, organizational level strategies directed at revisions in professional roles such as educational material, reminders and feedback were found to be relatively strong components of multi-faceted interventions (Dijkstra, 2006).

The strategic role that managers and supportive infrastructures have in fostering effective research transfer and subsequent practice change is highlighted in an integrative review of managerial leadership (Gifford, 2007). Management support positively influenced nurses’ use of research. Organizational issues such as hierarchal reporting structures acted as barriers to managers’ ability to affect research use. Another review evaluating the impact of facilitator/leader mediated interventions found that providing face-to-face communication and using a range of enabling techniques has some impact on changing clinical and organizational practice (Loftus-Hills, 2000).

While our knowledge of how best to implement guidelines into practice is “imperfect,” a systematic review looking at strategies for guideline implementation found that dissemination of guidelines, reminders, educational outreach and materials, audit and feedback did impact implementations (Grimshaw, 2006). Introduction to such interventions require organizational buy-in and infrastructure support.

In other examples, the National Health Service in the UK has instituted a pathway where patients with early prostate cancer meet with a urology specialist nurse who provides a decision aid and decision coaching (Archer, 2005). Results from the pilot project found that both patients and professionals found the decision aid and nurse coaching helpful in supporting the decision-making process. In the US, the state of Washington legislated evidence of decision support as part of informed consent. Working with organizations such as Accreditation Canada (formerly the Canadian Council for Health Services Accreditation) may facilitate national standards around patient decision support and the development of tools and resources as an implicit part of quality patient care opportunities.

The development of effective and targeted guideline implementation and sustainability strategies requires organizational commitment. An early and critical step in implementing guidelines is the formal adoption of the guidelines. Implementation strategies should address barriers related to the individual practitioner, as well as social, organizational and environmental cultures. Strategies should also be tailored to different groups of stakeholders (i.e., nursing staff, project leaders and administrators) (Ploeg, Davies, Edwards, Gifford & Elliott-Miller, 2007).
Ways administrators can facilitate decision support:

- Clearly articulate a corporate objective to integrate BPGs into clinical practice;
- Allocate human and other resources for guideline implementation activities (e.g., staff education, supplies);
- Identify and support champions for guideline implementation;
- Support guideline implementation through policies and documentation tools;
- Plan and carry out guideline implementation;
- Create infrastructure and systems that facilitate interprofessional communication and care planning (e.g., integrated case management).

For example, Ashby et al. (2005) highlights the need to promote policy changes to the renal management of end-of-life care. Techniques for doing this include clinical guidelines, advance directives, advanced care planning, peer mentoring programs, clinical and health promoting palliative care initiatives and bereavement support in order to help patients and families have a smoother path through the process of dying from dialysis withdrawal (discontinuation) or withholding (non-initiation), if such decisions are taken.

Best practice guideline implementation requires strong leadership. RNAO has developed the Toolkit: Implementation of Clinical Practice Guidelines (2002) to support nursing and organization leaders.

To download the Toolkit, at no cost, please visit www.rnao.org/bestpractices/PDF/BPG_Toolkit.pdf. Refer to Appendix L for a description of the Toolkit.

**RECOMMENDATION 8**
Organizations and regional health authorities develop and monitor key indicators of evidence-based patient decision support.

Type of Evidence: III

**Discussion of Evidence:**

A commitment to monitoring the impact of the implementation of the *Decision Support for Adults Living with Chronic Kidney Disease* best practice guideline is a key step that must not be omitted if there is to be an evaluation of the impact of the efforts associated with implementation. It is suggested that each recommendation to be adopted be described in measurable terms and that the health care team be involved in the evaluation and quality monitoring processes.

**Organizational Actions**
A robust quality assurance plan needs to include strategies to monitor quality decision support indicators.

Examples of key indicators and outcome measures to monitor include:

- Use of decision support interventions;
- Impact of decision support interventions on patient outcomes and service use;
- Effectiveness of patient decision support interventions.
Table 8 illustrates some examples of indicators for monitoring and evaluation of the guideline Decision Support for Adults Living with Chronic Kidney Disease.

**Table 8: Indicators for Monitoring and Evaluation of Guideline**

<table>
<thead>
<tr>
<th>LEVEL OF INDICATOR</th>
<th>STRUCTURE</th>
<th>PROCESS</th>
<th>OUTCOME</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult with CKD</td>
<td>Patients have access to reliable and evidence-based information to inform their decision. Patients have access to health care providers with skill and confidence in decision support and coaching strategies.</td>
<td>Patients verbalize to their health care provider when experiencing decisional conflict. Patients are provided with validated tools for use to guide the decision making process.</td>
<td>Documented evidence in the health record that the patient was exposed to decision support. Percentage of patients who start their chosen treatment as planned or rationale for not proceeding with the chosen treatment is documented. Documentation in the health record of patient’s degree of confidence with decision. Documentation of advanced directives in the health record.</td>
</tr>
<tr>
<td>Nurse</td>
<td>Nurses with the knowledge of patient decision support and/or CKD are available.</td>
<td>Nurses identify their learning needs. Educational resources (CKD and decision support) for nurses. Nurses pursue relevant educational activities.</td>
<td>Completion of educational programs related to decision support. Documented evidence of the provision of decision support in the patient health record.</td>
</tr>
<tr>
<td>Health Care Organization</td>
<td>Incorporation of decision coaching into strategic plans for the care of adults with CKD. Review of best practice recommendations by organizational committee(s) responsible for policy/procedures. Evidence-based patient decision support education programs.</td>
<td>Modifications to policy and procedures consistent with the recommendations to support decision making in adults with CKD. Development and delivery of continuing professional development activities, orientation and clinical mentorship programs integrating evidence-based patient decision support strategies.</td>
<td>Evidence that decision support interventions are integrated into processes of care (i.e., care pathways, documentation). Reduction in number of emergent dialysis starts. Reduction in number of inpatient hospital days associated with dialysis starts. Evidence of documentation of patient-identified chosen treatment option. Percentage of patients started on their treatment of choice. Availability of evidence-based patient decision support education. Availability of clinical mentors for decision support. Number of education sessions focused on decision support offered per year to health care professionals. Percentage of health care professionals attending the decision support education sessions offered.</td>
</tr>
</tbody>
</table>
Research Gaps and Future Implications

Evidence-based decision support is in the early stage of adoption in the context of CKD. Areas for further inquiry could focus on foundational studies to elicit patient decision-making needs, development of tools to measure decisional conflict/shared decision making in the context of CKD and pragmatic implementation trials to assess the impact of targeted evidence-based decision support interventions. Inquiry and evaluation formed around four interrelated domains could enhance our understanding and ability to best support adults living with CKD in their health decision making. These domains are:

1. Capacity building aimed at informing, influencing and assisting nurses and organizations to gain confidence and competence in providing quality end-of-life care for patients living with end-stage chronic conditions (e.g. integration in post licensure education, undergraduate curriculum).

2. Regulation and legislation aimed at embedding indicators of decision quality in legislation and policy (i.e., accreditations standards, scope of practice regulation).

3. Research designed to identify indicators of quality decision making relevant to the diverse population of patients living with CKD and application and evaluation of knowledge in practice.

4. Health efficiency evaluations to balance the cost, accessibility and effectiveness of care for patients living with CKD (i.e., what, to whom, by whom, how, with what effect) (Adapted from Lavis, 2003).

Many of the recommendations in this guideline are based on evidence gained from qualitative or quantitative research, while others are based on consensus or expert opinion. Further substantive research is required in some areas to validate the expert opinion that will lead to improved practice and outcomes related to the quality of decisions made by patients and families living with CKD.
Process for Review and Update of Guideline

The RNAO will review and update this best practice guideline every three years with a team of specialists.

1. During the three-year period between development and revision, RNAO program staff and a volunteer team from the original development panel will regularly monitor for new systematic reviews and randomized controlled trials and other relevant literature in the field.

2. Program staff will recommend earlier revision if needed. Appropriate consultation with a team comprising of original panel members and other specialists in the field will help inform the decision to review and revise the guidelines earlier than the three-year milestone.

3. Three months prior to the three-year review milestone, the program staff will commence the planning of the review process by:

   a) Inviting specialists in the field to participate in the Review Team. The Review Team will be comprised of members from the original panel as well as other recommended specialists.
   b) Compiling feedback received, questions encountered during the dissemination phase and other comments and experiences of implementation sites.
   c) Compiling new clinical practice guidelines in the field, systematic reviews, meta-analysis papers, technical reviews, randomized controlled trial research and other relevant literature.
   d) Developing detailed work plan with target dates and deliverables.

4. The revised guideline will undergo dissemination based on established structures and processes.
References


the prevention and management of diabetes in Canada. *Canadian Journal of Diabetes;* 32(Suppl 1), 37

www.nms.on.ca/Elementary/canada.htm

Available: www.chsrf.ca/other_documents/evidence_e.php#definition

Canadian Hypertension Education Program (2009). *Management and Prevention of Hypertension in Canada*
[Online]. Available: www.hypertension.ca/chep

Canadian Institute for Health Information (CIHI) (2008). Treatment of end stage organ failure in Canada 1997
to 2006. *Canadian Organ Replacement Register*. Retrieved Feb. 6, 2009 from


practice/guidelines

shared treatment decision model. *Social Science & Medicine,* 49(5), 651-661.

9(4), 977-992.

College of Nurses of Ontario (CNO) (2002). *Professional standards for registered nurses and registered practical

policy/41052_RHPAscope.pdf

Available: www.cno.org/docs/prac/41033_Therapeutic.pdf

Available: www.cno.org/docs/qa/44028_CRT.pdf

Sciences,* 325(4), 163-167.

management experience of people with mild to moderate chronic kidney disease. *Nephrology Nursing Journal,*
35(2), 147-155.

1199-1201.

*British Medical Journal,* 335(7609), 24-27.


Hurst, S.A. (2004). When patients refuse assessment of decision making capacity. Archives of Internal Medicine, 64(16), 1757-1760.


Marron, B., Ocana, J., Salgueira, M., Barril, G., Lamas, J., Martin, M., et al., on behalf of the Spanish group for


REFERENCES


Bibliography


## Appendix A: Glossary of Terms

**Advance Care Planning (ACP):** The communication process in which patient’s preferences for end-of-life care and surrogate decision maker are identified (Holley et al., 1999).

**Advanced Directive (for health or personal care):** Consists of instructions given by a capable person, often in written form, about their wishes for health care (treatment) and/or personal care in the event that they become incapable of giving informed consent. The advanced directive may appoint a proxy who will assume responsibility for ensuring that the person’s wishes are respected (Health Canada, 2006).

**Chronic Kidney Disease (CKD):** Irreversible kidney damage or a glomerular filtration rate of < 60ml/min/1.73m² for three or more months, irrespective of cause (Levey et al., 2003, p.138).

**Clinical Practice Guidelines or Best Practice Guidelines:** Systematically developed statements to assist practitioner and client decisions about appropriate health care for specific clinical (practice) circumstances (Field & Lohr, 1990).

**Consensus:** A process for making policy decisions, not a scientific method for creating new knowledge. Consensus development makes the best use of available information, be that scientific data or the collective wisdom of the participants (Black et al., 1999).

**Estimated GFR (e-GFR):** An estimate of the filtering capacity of the kidneys. As total GFR reflects functioning kidney mass, a decrease in GFR indicates a decline in kidney function (K/DOQI, 2000). While numerous equations are available, the CSN (2007) recommends the Modification of Diet in Renal Disease equation (MDRD). To calculate eGFR, including the International System of Units (SI) conversion, see [http://ukidney.com/egfr-calculator.html](http://ukidney.com/egfr-calculator.html) or [http://www.kidney.org/professionals/kdoqi/gfr_calculator.cfm](http://www.kidney.org/professionals/kdoqi/gfr_calculator.cfm)

**Education Recommendations:** Statements of educational requirements and educational approaches/strategies for the introduction, implementation and sustainability of the best practice guideline.

**Evidence:** Evidence is information that comes closest to the facts of a matter. The form it takes depends on context. The findings of high-quality, methodologically appropriate research are the most accurate evidence. Because research is often incomplete and sometimes contradictory or unavailable, other kinds of information are necessary supplements to, or stand-ins for, research. The evidence base for a decision is the multiple forms of evidence combined to balance rigor with expediency – while privileging the former over the latter (Canadian Health Services Research Foundation, 2006).
Hemodialysis: The removal of solutes and water from the circulating blood, across a semipermeable membrane (dialyzer) (Thomas, 2002). Hemodialysis requires access to the circulation (vascular access) and may be carried out in either a home or institutional setting.

Informed Consent: Agreement to a health care treatment given by a capable person who is able to understand and appreciate the nature and consequences of the proposed treatment. If a person is incapable of giving consent, a proxy or substitute decision maker may give consent in their place. Unless there is an emergency such that informed consent cannot be obtained, full and informed consent is the standard required for any health care treatment. The option of no treatment is specified as a possibility for informed consent in some legislation (Health Canada, 2006).

Nephrology Nursing: A specialized area of nursing practice which focuses on the nursing care needs of patients of all ages with renal dysfunction, and their families, throughout the course of illness and treatment (CANNT, 2008).

Organization and Policy Recommendations: Statements of conditions required for a practice setting that enables the successful implementation of the best practice guideline. The conditions for success are largely the responsibility of the organization, although they may have implications for policy at a broader government or societal level.

Palliative Care: An approach that improves the quality of life of patients and their families who are facing problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification, assessment and treatment of pain and other problems (physical, psychosocial and spiritual) (Sepulveda et al., 2002).

Peritoneal Dialysis: The removal of solutes and water from the circulating blood through principles of diffusion and osmosis, using the peritoneal membrane as a dialyzer (Wild, 2002). Dialyzing solution is instilled into the peritoneal cavity through a peritoneal catheter. There are different types of peritoneal dialysis, including continuous ambulatory peritoneal dialysis (CAPD) and automated or continuous cycle peritoneal dialysis (APD, CCPD) (Kidney Foundation of Canada, 2008).

Practice Recommendations: Statements of best practice directed at the practice of health care professionals that, ideally, are evidence based.

Randomized Controlled Trials: Clinical trials that involve at least one test treatment and one control treatment, concurrent enrollment and follow-up of the test- and control-treated groups, and in which the treatments to be administered are selected by a random process.
Stakeholder: An individual, group or organization with a vested interest in the decisions and actions of organizations that may attempt to influence decisions and actions (Baker et al., 1999). Stakeholders include all individuals or groups who will be directly or indirectly affected by the change or solution to the problem.

Substitute Decision Maker: The general term used to designate a person who is appointed to make health and/or personal care decisions on behalf of a person who is incapable of giving informed consent. A proxy is a substitute decision maker appointed in an advance directive. If there is no advance directive naming a proxy, then next of kin or other substitute decision makers (e.g. friends or health care providers) will usually be named in legislation to act in a hierarchical order, beginning with the spouse (Health Canada, 2006).

Systematic Review: An application of a rigorous scientific approach to the preparation of a review article (National Health and Medical Research Centre, 1999). Systematic reviews establish where the effects of health care are consistent and research results can be applied across populations, settings and differences in treatment (e.g. dose); and where effects may vary significantly. The use of explicit, systematic methods in reviews limits bias (systematic errors) and reduces chance effects, thus providing more reliable results upon which to draw conclusions and make decisions (Alderson, Green & Higgins, 2004).

Therapeutic Relationship: The therapeutic relationship is grounded in an interpersonal process that occurs between the nurse and the client(s). Therapeutic relationship is a purposeful, goal directed relationship that is directed at advancing the best interest and outcome of the client (RNAO, revised 2006).
Appendix B: Guideline Development Process

The RNAO, with funding from the Government of Ontario, has embarked on a multi-year program of nursing best practice guideline development, pilot implementation, evaluation, dissemination and support of uptake. One of the areas of emphasis is on nursing interventions related to adults living with chronic kidney disease and the decisions needed to be made during the trajectory of this illness. This guideline was developed by a panel of nurses and other health professionals convened by the RNAO. This work was conducted independent of any bias or influence from the Ontario Government. No personal renumeration has been carried out.

In August 2007, the RNAO convened a focus group of CKD experts. This group recognized the complexity of CKD and the diversity of options for a nursing best practice guideline for CKD. The group recognized the important body of evidence related to chronic disease management, but identified that strategies to engage patients are not clearly described. Decision support is an effective strategy to engage patients in self-management.

In November of 2007, a panel with expertise in practice, education and research, from hospital, community and academic settings, was convened under the auspices of the RNAO. The panel discussed the purpose of their work, and came to consensus on the scope of the best practice guideline.

Subsequently, a search of the literature was conducted for clinical practice guidelines, systematic reviews, relevant research studies and other types of evidence. A systematic review (Murray et al., in press) was conducted to inform this process, and will be published separately; see Appendix C for brief details of the search strategy and outcomes.

Several international guidelines related to CKD were critically appraised and chosen to inform the development of this guideline. Eighteen clinical practice guidelines were identified that met the following initial inclusion criteria:

- published in English
- developed in 2000 or later
- strictly on the topic of CKD
- evidence based and
- available and accessible for retrieval

Members of the development panel critically appraised these 18 guidelines using the Appraisal of Guidelines for Research and Evaluation Instrument (AGREE Collaboration, 2001). This review resulted in the decision that eight of these guidelines were relevant to the scope of the current project and would be used to inform the development process (Jindal et al., 2006; NKF, 2002, 2006, 2007; Peritoneal Dialysis Adequacy Work Group, 2006; Renal Physicians Association and American Society of Nephrology [RPA & ASN]), 2000; Vanholder et al., 2006).
The panel members were divided into subgroups to synthesize the short listed guidelines, evidence summaries, studies and other literature for the purpose of drafting recommendations for nursing assessment and interventions. This process resulted in the development of practice, education and organization and policy recommendations. The panel members collectively reviewed the first draft of recommendations, discussed gaps, reviewed the evidence and came to consensus on a final set of recommendations.

This draft was submitted to a set of external stakeholders for review and feedback – an acknowledgement of these reviewers is provided at the front of this document. Stakeholders represented various health care professional groups, clients and families, as well as professional associations. External stakeholders were provided with specific questions for comment, as well as the opportunity to give overall feedback and general impressions. In addition, client and family focus groups were conducted to gather feedback on the draft recommendations.

To get a better understanding of the patient’s preferred role in decision making, this panel decided to undertake a focus group as part of the stakeholder review process. The focus group, consisting of patients with CKD and their family/support persons, was held in August 2008 to review this guideline. The session was led by a panel member with the purpose of obtaining patient feedback on the draft of recommendations from the patient perspective. The development methodology, scope, purpose and recommendations were discussed with the group. A group feedback form was utilized as well as group discussion. Each recommendation was reviewed and discussed with focus group members who were asked if the recommendation was clearly stated and if they agreed with the recommendation. This was followed by a general comment period, including a query regarding any significant gaps. The overall feedback was positive, with patients wanting nurses to be empowered to assist patients with CKD by providing information, education and support.

Finally, panel members appraised the draft document using the AGREE tool (AGREE, 2001). The feedback from stakeholders and panel members were compiled and reviewed by the development panel – discussion and consensus resulted in revisions to the draft document prior to publication.
Appendix C: Process for Systematic Review and Search Strategy

The search strategy utilized during the development of this guideline focused on two key areas. One was the identification of clinical practice guidelines published on the topic of decision support for CKD and the second was to identify systematic reviews and primary studies published in this area from 2001 to 2008.

STEP 1 – DATABASE Search

A database search for existing evidence related to decision support and chronic kidney disease was conducted by a health sciences librarian using search terms generated by the development panel. The search strategy utilized by the Cochrane Effective Practice and Organization of Care group was used to formulate the final search strategy. Databases searched included the Cochrane Database of Systematic Reviews, the Cochrane Central Register of Controlled Trials, MEDLINE (1996 to October 2007), CINAHL (1982 to December 2007), PsycINFO (1985 to January 2008), EMBASE (1980 to 2008), as well as the Patient Decision Aid Register (OHRI, University of Ottawa). Key journals were hand-searched from 2004 to 2008 (Medical Decision Making; BMC Medical Informatics and Decision Making; Kidney International; Peritoneal Dialysis International; American Journal of Kidney Diseases) and author searches were conducted for additional publications by researchers in decision support.

Studies were included if they met the following criteria:
- Published in English
- Published between 1998 and 2008
- Study samples included only adults (≥ 18 years) with chronic kidney disease

A systematic review (Murray et al. [in press]) was generated to summarize the results of these efforts. This review of the current literature was conducted to identify factors influencing patient decision making related to CKD. More specifically, the systematic review was structured to identify the following issues:

1. describe factors related to key patient decisions, information and decision-making needs;
2. identify and review the quality of decision support tools;
3. explore barriers and facilitators to providing patient decision support; and
4. describe the impact of decision support on decision quality in the context of adults living with CKD.

As directed by the panel, additional literature searches were conducted to supplement the results of the systematic review report, where needed.
STEP 2 – Structured Website Search

One individual searched an established list of websites for content related to the topic area in November 2007. This list of sites was compiled based on existing knowledge of evidence-based practice websites, known guideline developers and recommendations from the literature. Presence or absence of guidelines was noted for each site searched as well as date searched. The websites at times did not house guidelines, but directed to another website or source for guideline retrieval. Guidelines were either downloaded if full versions were available or were ordered by phone/email.

- Agency for Healthcare Research and Quality: www.ahrq.gov
- Alberta Medical Association – Clinical Practice Guidelines: www.albertadoctors.org
- American Nephrology Nurses’ Association: www.annanurse.org
- Annals of Internal Medicine: www.annals.org
- Bandolier Journal: www.jr2.ox.ac.uk/bandolier
- British Columbia Council on Clinical Practice Guidelines: www.bcguidelines.ca/gpac
- BC Office of Health Technology Assessment: www.chspr.ubc.ca
- Campbell Collaboration: www.campbellcollaboration.org
- Canadian Coordinating Office for Health Technology Assessment: www.ccohta.ca
- Canadian Hypertension Education Program: www.hypertension.ca/chep
- Canadian Institute of Health Information: www.cihi.ca
- Canadian Society of Nephrology: www.csnscn.ca
- Caring for Australasians with Renal Impairment: www.cari.org.au
- Centers for Disease Control and Prevention: www.cdc.gov
- Centre for Evidence-Based Mental Health: http://cebmh.com
- Clinical Evidence: www.clinicalevidence.org
- Clinical Resource Efficiency Support Team (CREST): www.crestni.org.uk
- Canadian Medical Association Journal: www.cmaj.ca
- Cochrane Library: Abstracts of Cochrane Reviews: www.thecochranelibrary.com
- Database of Abstracts of Reviews of Effectiveness (DARE): www.crd.york.ac.uk/crdweb
- European Observatory on Health Care for Chronic Conditions, World Health Organization: www.euro.who.int/observatory
- Evidence-based On-Call: www.eboncall.org
- Guidelines Advisory Committee: www.gacguidelines.ca
- Guidelines International Network: www.g-i-n.net
- Health Evidence: www.health-evidence.ca
- Health Evidence Network, European Region, World Health Organization: www.euro.who.int/HEN
- Institute for Clinical Evaluative Sciences: www.ices.on.ca
- Institute for Clinical Systems Improvement: www.icsi.org/index.asp
- Institute of Intergovernmental Relations, Queen’s University: www.iigr.ca
- Joanna Briggs Institute: www.joannabriggs.edu.au
In addition, panel members were encouraged to present any other guidelines they were aware of to the rest of their panel colleagues for review/consideration.

SEARCH RESULTS:

For details of the search results, please refer to Supporting Adults Living with Chronic Kidney Disease (CKD) in Making Choices: A Systematic Review of Patient Information and Decision Support Needs (Murray et al., in press).
Appendix D: Management Regimes and Lifestyle Changes Associated with CKD

Living with CKD involves making decisions around medical management and lifestyle changes. The following tables outline some of the more common elements of CKD management and resources for obtaining further information. The list is by no means exhaustive.

Medical Management
Applicable to CKD Stages 1-5

<table>
<thead>
<tr>
<th>HEALTH ISSUE</th>
<th>RATIONALE</th>
<th>RESOURCES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes</td>
<td>Patients with diabetes are at risk for CKD and cardiovascular events</td>
<td>CDA, 2008; CSN 2009; Levin et al., 2008</td>
</tr>
<tr>
<td>Cardiovascular Disease</td>
<td>Hypertension is both a cause and a consequence of CKD</td>
<td>CSN 2009; Levin et al., 2008</td>
</tr>
</tbody>
</table>
| Medication Regimens | Complicated regimens of medications intended to control the progressions of CKD and/or reduce complications or symptoms associated with CKD are often prescribed. These may include medications to:  
- Manage diabetes, hypertension, and anemia  
- Control renal bone disease  
- Maintain acid/base and electrolyte balance  
- Reduce cardiovascular risk factors  
- Reduce the risk of transplant rejection  
NOTE: There is a risk of acute decline in kidney function with the use of non-steroidal anti-inflammatory drugs, certain doses or types of antibiotics/antimicrobials, and radiographic contrast dye | CHEP 2009; CSN 2009; K/DOQI CKD, 2002 |

Lifestyle Changes
Applicable to CKD Stages 1-5

<table>
<thead>
<tr>
<th>LIFESTYLE CHANGE</th>
<th>RATIONALE</th>
<th>RESOURCES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dietary Interventions</td>
<td><strong>Evaluation</strong> and counselling by a registered dietitian is strongly recommended</td>
<td>CSN, 2009</td>
</tr>
<tr>
<td></td>
<td><strong>Dietary modifications</strong> typically include fluid, protein, potassium and phosphate intake, and salt restriction</td>
<td>K/DOQI CKD, 2002</td>
</tr>
<tr>
<td></td>
<td><strong>Dietary regimens</strong> may be difficult for patients who require multiple regimens (e.g. diabetes and cardiac diets, as well as renal)</td>
<td>Canada’s Food Guide, 2009</td>
</tr>
<tr>
<td></td>
<td><strong>Adults</strong> with advanced CKD may be at risk for protein-energy malnutrition due to uremia, altered taste sensations, coexisting illnesses, and/or anorexia</td>
<td>K/DOQI CKD, 2002</td>
</tr>
<tr>
<td>LIFESTYLE CHANGE</td>
<td>RATIONALE</td>
<td>RESOURCES</td>
</tr>
<tr>
<td>----------------------</td>
<td>------------------------------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| Healthy Weight       | **Obesity** is a strong and potentially modifiable risk factor for the development and progression of kidney disease  
                        **Being overweight** is a modifiable risk factor for developing hypertension and cardiovascular disease  
                        **Weight loss** strategies should include a multidisciplinary approach, focusing on dietary education, increasing exercise and behaviour modification | Heart and Stroke Foundation, 2008; K/DOQI CKD, 2002; Wang, 2008;  
                                                                                  Heart and Stroke Foundation, 2008  
                                                                                  CSN, 2009                                                                                         |
| Exercise             | **Exercise** is beneficial in the prevention and management of hypertension and to improve blood sugar control, increase fitness, and reduce morbidity in patients with diabetes  
                        **Moderate intensity activity** for 30 minutes per day, most days of the week, is recommended | CDA, 2008; CHEP, 2009; K/DOQI Diabetes and CKD, 2007; K/DOQI, 2000                                                                                        |
| Smoking Cessation    | **Smoking** may be associated with a faster decline in kidney function  
                        **Smoking cessation** is also recommended to reduce cardiovascular risk, especially for patients with diabetes and hypertension | Haroun et al., 2003; Henry et al., 2003; Jones-Burton et al., 2007; CDA, 2008  
                                                                                  CSN, 2009; CHEP, 2009; K/DOQI CKD, 2002                                                                  |
| Alcohol Consumption  | **Alcohol intake** of four or more servings (1.5oz or 45ml of spirits; 5oz or 150ml of wine; 12oz or 375ml of beer) a day is associated with CKD | K/DOQI CKD, 2002; CHEP, 2009; Shankar, 2006                                                            |

**Treatment Decisions**  
Applicable to CKD Stages 3-5.

The decision to choose a form of renal replacement therapy is a values-sensitive decision and requires considerable decision support. For further treatment information, refer to the Background Context on CKD, p. 19.

<table>
<thead>
<tr>
<th>TREATMENT DECISION</th>
<th>RATIONALE</th>
<th>RESOURCE</th>
</tr>
</thead>
</table>
| Renal Replacement Therapy (RRT) Options:  
  - Peritoneal Dialysis  
  - Hemodialysis  
  - Transplantation | RRT decisions may be influenced by:  
  - Availability of resources  
  - Capacity and willingness to participate  
  - Caregiver support  
  - Cognitive ability  
  - Geography  
  - Physical ability and health status  
  - System resources (human and financial)  
  - Technical and practical considerations (water supply, space, burden of therapy) | K/DOQI, 2000;  
                                                                                  Jindal et al., 2006                                                             |
Renal Replacement Therapy (RRT) Options:
- Peritoneal Dialysis
- Hemodialysis
- Transplantation

<table>
<thead>
<tr>
<th>TREATMENT DECISION</th>
<th>RATIONALE</th>
<th>RESOURCE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Choice of a treatment option will lead to further decisions:</td>
<td></td>
<td>K/DOQI, 2000</td>
</tr>
<tr>
<td>Access creation: The type of hemodialysis access most suitable is determined by an in-depth evaluation of the patient’s vessels and cardiovascular system, life expectancy or duration of treatment. Plans for creation of a hemodialysis access should be made in advance of dialysis initiation.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grafts may be used after 2 to 4 weeks</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fistulas should be allowed to mature for 3 to 4 months</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adhering to a dialysis schedule (influenced by values, ability to get to treatment, care provider’s ability, wellness)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A “trial of dialysis” for an individual patient is an option to explore to determine if the quality of life provided is greater than the quantity and might be considered when there is an uncertain prognosis, or when decision makers do not have consensus</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The degree of participation from self-care (home peritoneal dialysis, home hemodialysis) to full assistance (in-centre hemodialysis)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The location and scheduling of dialysis (home, intermittent hemodialysis, nocturnal hemodialysis, daily dialysis, travel options)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>When to initiate treatment (delaying dialysis can lead to increased risk of malnutrition, fluid volume overload and other metabolic complications. However, starting dialysis too early exposes the patient to the inherent risks of the treatment.)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Choice of transplantation may improve quality and length of life. The options includes further decisions:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A live kidney donor transplant may be refused due to concerns for the donor’s well-being and the potential to compromise the relationship with the donor.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deceased kidney donor transplants have a shorter lifespan than a live kidney donor transplant:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>70% of deceased donor kidney transplants are still functioning after 5 years</td>
<td></td>
<td>Nolan et al., 2004; Yi, 2003</td>
</tr>
<tr>
<td>90% of living kidney donor transplants are still functioning after 5 years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deceased kidney donor transplants take longer to obtain (5 + years; wait times vary depending on the centres)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transplants are less costly to the health care system, but individual cost of travel and medications may impact the decision to consider this treatment option</td>
<td></td>
<td>CIHI, 2008</td>
</tr>
</tbody>
</table>
Resuscitation Status

**Resuscitation decisions** are very values-sensitive. Preferences should be assessed and respected.

Few dialysis patients implement a “Do Not Resuscitate” directive despite the extremely poor chance of survival in this group after CPR.

Choosing not to have renal replacement therapy (conservative management) or the withdrawal from therapy and planning for end-of-life care decisions are particularly values-sensitive decisions.

Choosing “no dialysis” is not “no treatment,” but rather choosing palliative care and support.

Conservative/End-of-Life Care includes:
- Psychological Care
- Spiritual Care
- Symptom Management

These decisions should be a shared decision-making process including the following, as appropriate:
- Advance directives (See Appendix F)
- Conflict resolution
- Estimating prognosis
- Informed consent
- Palliative care
- Time-limited trials of dialysis may be undertaken to assess impact on quality of life
- The decision to not begin, or to withdraw from, dialysis

Three main values-sensitive issues should be considered:
- Communication and support
- Quality of life, pain and suffering
- Self-perceived burden

Davison, 2006; Miura, 2001; Moss, 2001

Refer to Appendix E for a series of sample questions to facilitate discussions regarding CPR

Advanced Care Planning

Conservative Management

End-of-Life Care

Additional Decisions

Applicable to CKD Stages 3-5.

**Family Planning**

The presence of CKD may complicate these values-sensitive decisions:
- Genetic testing: Some kidney diseases are familial or hereditary (e.g. polycystic kidney disease)
- Pregnancy: CKD may increase the risk of maternal or fetal complications (loss of kidney function, low birth weight, congenital abnormalities); maternal medications may need to be adjusted
- Medications may have teratogenic effects

Imbasciati et al., 2007; Ramin et al., 2006; Williams, 2007

Refer to Appendix G for common RRT medications and their effects in pregnancy

Magee, 2001; Ramin et al., 2006
Appendix E: Cardiopulmonary Resuscitation (CPR) – A Questionnaire for Dialysis Patients
(Adapted from Miura et al., 2001)

The following is a series of sample questions to facilitate a discussion about whether or not a patient on dialysis desires CPR.

1. If your heart and breathing had stopped in your current health status because of cardiac or brain stroke, would you want to have CPR?

2. Suppose that you have developed serious dementia from Alzheimer’s disease. You have lost self-perception, are unable to recognize your family and have become completely dependent. Your medical status requires help for diet, walking and having a bath.
   a) Would you want to continue dialysis treatment in the situation described above?
   b) Would you want to have CPR if your heart and breathing had stopped in the situation described above because of cardiac arrest or brain stroke?

3. Suppose that you have terminal cancer with an expected survival of 6 months. You are alert and competent. Pain can be controlled by medication.
   a) Would you want to continue dialysis treatment in the situation described above?
   b) Would you want to have CPR if your heart and breathing had stopped in the situation described above because of cardiac arrest or brain stroke?

4. Have you ever discussed your preferences regarding CPR with your family members?

5. Have you ever discussed your preferences regarding CPR with your physician?
Appendix F: Open-Ended Questions to Promote Discussions for Advanced Care Planning  (Holley, 2007, p.405)

Addressing goals of care when prognosis is uncertain
- What are your most important hopes?
- What concerns you most about your illness?
- What is your quality of life like now?
- Is it more important for you to live as long as possible, despite some suffering, or to live without suffering for a shorter length of time?
- What are your biggest fears?
- Given the severity of your illness, what is most important for you to achieve?
- What do you understand about your illness?
- How much do you want to know?

Advance-care planning and end-of-life issues

Values
- What makes life most worth living to you?
- Are there circumstances in which you would find life not worth living?
- Have you seen or been with someone who had a particularly good (or difficult) death?
- What have been the worst and the best things about this illness for you?

Directives
- If you are unable to speak for yourself in the future, who would be best able to represent your views and values? (substitute decision maker)
- Have you given any thought to what kinds of treatment you would want, or not want, if you become unable to speak for yourself in the future? (advanced directive)
- Have you considered circumstances in which you would want to stop dialysis?
- Where would you like to be and who would you like to be there when you die?
Appendix G: Common Renal Replacement Therapy Medications and their Effects in Pregnancy
(Blowey & Warady, 1998; Pergola et al., 2001; Williams, 2007)

<table>
<thead>
<tr>
<th>MEDICATION</th>
<th>POTENTIAL TERATOGENIC EFFECTS</th>
<th>GESTATIONAL RISK PERIOD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Angiotensin converting enzyme (ACE) inhibitors</td>
<td>Fetal hypertension, anuria-oligohydramnios growth restriction, pulmonary hypoplasia, renal tubular dysphasia, hypocalvaria</td>
<td>Second and third trimester</td>
</tr>
<tr>
<td>Cyclosporine, Azathioprine, Steroids</td>
<td>Prematurity, hyaline membrane disease, hyperbilirubinemia, patient ductus arteriosus, transient hyponatremia</td>
<td>Throughout gestation period</td>
</tr>
<tr>
<td>Tacrolimus Immunosuppression</td>
<td>Prematurity</td>
<td>Throughout gestation period</td>
</tr>
<tr>
<td>Mycophenolate mofetil Immunosuppression Steroids</td>
<td>Prematurity, hypoplastic finger and toenails and shortened fifth fingers bilaterally, apnea and bradycardia with feeds aberrant blood vessel between trachea and esophagus</td>
<td>Throughout gestation period</td>
</tr>
</tbody>
</table>

Appendix H: Resources

The following educational resources have been compiled by the development panel to help nurses and their clients learn more about decision support for patients and families living with CKD. It is not intended to be an inclusive listing; Canadian resources are listed first, with the remainder in alphabetical order:

- name and website
- description
- examples of resources available to the public on the website

Nephrology-Related Resources

Canadian Association of Nephrology Nurses and Technologists (CANNT) (www.cannt.ca)
This Canadian voluntary, not-for-profit organization is dedicated to promoting the dissemination of knowledge among those involved in the care of patients with renal disease. Efforts are directed toward improving the care of renal patients through formal and informal educational projects for CANNT members in the following sub-specialties (both adult and pediatric): Technology, Hemodialysis, Peritoneal Dialysis, Transplantation and Progressive Renal Insufficiency (Pre-Dialysis).
Kidney Foundation of Canada (KFoC) (www.kidney.ca)
This Canadian volunteer organization is committed to reducing the burden of kidney disease through funding and stimulating innovative research; providing education and support; promoting access to high quality health care; and increasing public awareness and commitment to advancing kidney health and organ donation. This website is user friendly and is appropriate for patients, their families and nurses. Information on many topics can be found under the services tab on the homepage. The KFoC document Living with Kidney Disease (4th edition) is available, in PDF format, at www.kidney.ca/files/Kidney/aaCompleteManual.pdf.

American Nephrology Nurses’ Association (ANNA) (www.annanurse.org)
This American non-profit organization was created to advance nephrology nursing practice and positively influence outcomes for patients with kidney disease through advocacy, scholarship and excellence. Members work in areas such as conservative management, peritoneal dialysis, hemodialysis, continuous renal replacement therapies, transplantation, industry and government/regulatory agencies. Education resources can be found via the tabs down the left side of the homepage, which then direct users to a page spotlighting the care for older adults.

Edinburgh’s Royal Infirmary, Kidney Transplantation (EdREN) (http://renux.dmed.ed.ac.uk/EdREN/EdRenINFOhome.html)
This website from the United Kingdom was created to disseminate cutting edge information in a timely manner to patients, to health professionals who are not renal specialists and for anyone else who is interested in kidney diseases. The homepage shows an A-Z list of topics, and also tabs that lead to more specialized information.

Kidney Patient Guide (www.kidneypatientguide.org.uk)
This website from the United Kingdom came about as a result of collaboration between health care professionals; experts in information technology and multimedia; specialist health care writers; and people with renal failure and their families. This website provides information for renal patients, their partners and families, health care professionals and anyone else interested in kidney disease. It includes information not only on physical aspects of kidney failure – how the kidneys function, what happens when they don’t and the treatments available – but also on wider issues such as emotional, social and financial implications.

Kidney School (www.kidneyschool.org)
Kidney School is an American interactive, web-based learning program that is offered in modules. It was designed to help people learn what they need to know to understand kidney disease and its treatment, adjust to kidney disease, make good medical choices and provide the tools they need to self-manage care to stay healthier and live as fully as possible doing the activities they enjoy. From the homepage, click on the table of contents to start the modules.
National Kidney Foundation
(www.kidney.org)
This American foundation is a voluntary organization that seeks to prevent kidney and urinary tract diseases, improve the health and well-being of individuals and families affected by these diseases and increase the availability of all organs for transplantation. The goals of the organization include supporting research and research training; continuing education of health care professionals; expanding patient services and community resources; educating the public; shaping health policy; and fund raising. Information is available from the specific tabs (e.g. the patients tab), or from the A–Z index.

National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC)
(www.kidney.niddk.nih.gov)
NKUDIC is an American information clearinghouse, established to increase knowledge and understanding about diseases of the kidneys and the urologic system among those with these conditions and their families, health care professionals and the general public. To carry out this mission, NKUDIC works closely with a co-ordinating panel of representatives from federal agencies; voluntary organizations on the national level; professional groups; and state health departments to identify and respond to informational needs about kidney and urologic diseases. All this information is available through the homepage.

The Nephron Information Center
(www.nephron.com)
This American centre was designed to make the public more aware of kidney disease, to prevent it when possible, and to help colleagues achieve good outcomes in those who already have end-stage renal disease. They provide as much information as possible to patients, professionals and the general public, in the hopes that this education will be a motivating factor in making the necessary changes to prevent or stall chronic kidney disease. On the homepage there are links to informative areas including, but not limited to, CKD, KDOQI and nutrition. There is also a patient information tab.

RenalWEB
(www.renalweb.com)
RenalWEB is an American, non-affiliated website for the dialysis industry and community. With hundreds of websites containing dialysis product information, RenalWEB functions as a “daily newspaper” for useful information, new products, services and educational resources. Information for professionals and for patients learning about dialysis can be found under tabs for each heading.

Transplant Resources

Canadian Association of Transplantation (CAT)
(www.transplant.ca)
Membership in this Canadian association includes health professionals and partners who are involved in every aspect of organ and tissue donation and transplantation, including recovery, allocation and distribution of organs and tissues; managing care for patients pre and post transplant; and recognizing and supporting donor families. CAT is playing a critical role in the development of national guidelines and safety issues involving distribution of organs and tissues. There is excellent information, under the public information tab, on the topic of organ and tissue donation, in a myth vs. fact format, and information regarding organ transplantation.
Canadian Society of Transplantation (CST)
(www.cst-transplant.ca)
The aim of this society is to provide leadership for the advancement of educational, scientific and clinical aspects of transplantation in Canada. The Society’s Consensus guidelines on eligibility for kidney transplantation are available at: www.cmaj.ca/cgi/reprint/173/10/S1

Trillium Gift of Life Network (TGLN)
(www.giftoflife.on.ca)
Trillium Gift of Life Network, Ontario’s Organ and Tissue Donation Agency, was created to help save and enhance lives by maximizing organ and tissue donations for transplantation. Topics such as resources, programs, news, statistics and support can be found under tabs, or can be searched.

International Transplant Nurses Society (ITNS)
(www.itns.org)
This international non-profit society is committed to the promotion of excellence in transplant clinical nursing through the provision of educational and professional growth opportunities, interdisciplinary networking and collaborative activities and transplant nursing research. Canadian chapters can be located directly from the homepage. Educational brochures, found through the education tab on the homepage, are downloadable in PDF format.

United Network for Organ Sharing, Organ Donation and Transplantation
(www.unos.org)
This American network is a non-profit, scientific and educational organization that collects and manages data about every transplant event occurring in the US. It facilitates the organ matching and placement process using UNOS-developed data technology and the UNOS Organ Center, and brings together medical professionals, transplant recipients and donor families to develop organ transplantation policy. Patient education brochures can be found under the resources tab.

Other Resources

Registered Nurses’ Association of Ontario (RNAO)
(www.RNAO.org)
The International Affairs & Best Practice Guidelines Program (IABPG) is a signature program of RNAO focused on the development, dissemination, implementation and evaluation of clinical and healthy work environment best practice guidelines (BPGs). The program was launched in 1999 with multi-year funding from the Ontario Ministry of Health and Long-Term Care. There are currently over 30 published clinical guidelines, as well as a Toolkit and Educator’s Resource to support implementation. To date, 10 of the guidelines are available in French, with a continued dedication to translate materials on an ongoing basis. Examples of guidelines relevant to this guideline include: Integrating Smoking Cessation into Daily Nursing Practice and Nursing Management of Hypertension. Clinical Practice Guidelines and a variety of support materials are available for free download from www.RNAO.org.
Canadian Hypertension Education Program (CHEP)  
(www.hypertension.ca/chep)
This innovative knowledge translation program is designed to reduce the disease burden of sub-optimal blood pressure, the leading cause of death for patients on dialysis. CHEP provides practical, trustworthy, up-to-date knowledge for health care professionals.

Canadian Diabetes Association  
(www.diabetes.ca)
The Canadian Diabetes Association is a leading expert and authority on diabetes in Canada and around the world. Working in communities across the country to promote the health of Canadians and eliminate diabetes, CDA continues to deliver programs and services for people affected by diabetes. The CDA funds leading-edge diabetes research and produces globally recognized diabetes guidelines.

Appendix I: Key Features of Selected Decision Support Theories

Shared decision making is a process whereby patients and their health care professionals(s) consider health care options and reach agreement on the option that best fits with patients’ clinical needs, priorities and preferences (Stacey, 2008). Based on a review of 20 shared decision-making theoretical frameworks (Legare, 2008), strengths and limitations of five practice theories are summarized below. This subset was chosen based on the ability to encompass patients’ and health care professionals’ experience with CKD decision making from prevention, through treatment to palliation.

<table>
<thead>
<tr>
<th>PRACTICE THEORIES</th>
<th>KEY ELEMENTS</th>
<th>STRENGTHS</th>
<th>LIMITATIONS</th>
</tr>
</thead>
</table>
| Model for treatment decision making  
(Charles et al., 1997) | Paternalistic decision making: physician makes the decision alone  
Informed decision making: patient makes the decision alone  
Shared decision making: patient and physician make the decision together by:  
a) having a two-way exchange of information (physician providing medical information, patient providing their preferences)  
b) deliberating on the decision  
c) negotiating and agreeing on the treatment to implement | ■ Situates shared decision making within other approaches to decision making  
■ Flexible approach to structuring decision-making process to respect individual patient preferences for their involvement in decision making  
■ Evidence indicates that patients involved in decision making have better outcomes (Hack, 2006)  
■ Patients supported in decision making are more likely to have an active role in decision making (O’Connor, 2007) | ■ Focused on physician/patient dyad  
■ Choosing a style of decision making too early in the process, may result in a paternalistic approach; if patients had been supported with decision making, they would have preferred a shared role in making the decision |
### Decision Support for Adults Living with Chronic Kidney Disease

#### Decision Analytic Model (Rothert, 2008)
- **Information**: risks, benefits and likely outcomes
- **Values**: judgments and importance weights
- **Decision support interventions**: display elements on the decision and discuss the consequences (outcomes) of choosing one option over another
- **Decision**: measuring decisional conflict, satisfaction with the decision, satisfaction with the provider and self-efficacy
- **Behaviour**: adherence to the chosen treatment
- **Outcomes**: patient health status

**Key assumption**: information and values influence decisions; decisions affect behaviour; behaviour affects outcomes

**Strengths**: Developed by an interdisciplinary team, including nurses
- Includes a process for involving patients in decision making and using interventions
- Values decision support interventions as a means to improve decision quality

**Limitations**: Limited empirical testing: tested only in women considering hormone replacement therapy
- Decision and provider satisfaction may be due to factors not identified in the model (e.g. provider characteristics)
- Does not acknowledge other factors influencing decisions such as the environment, others' opinions, resources
- Focused on the dyad (patient, provider) and does not account for multiple players or surrogate decision makers

#### Ottawa Decision Support Framework (O’Connor, 1998)
- **Decisional conflict**: uncertainty about the best course of action
- **Knowledge of options**, benefits and harms based on best available evidence
- **Realistic expectations** of outcomes
- **Values associated** with outcomes of options
- **Internal and external support and resources** to influence decision making and implementing the decision
- **Decision quality**: reaching decisions that are congruent with patients’ informed values and priorities for taking action

**Strengths**: Developed by an interdisciplinary team, including nurses and based on multiple theories
- Includes a broad range of factors influencing decision making
- Tested in many different clinical settings

**Limitations**: Broader environmental factors are not considered (e.g. political issues)
- Minimal discussion of how concepts are linked
- More descriptive and does not address interactional issues
- Not as relevant for some decision situations (emergency situation; ethical and legal)
### PRACTICE THEORIES

- Decision coach mediated shared decision making (Stacey, 2008)
  - *Evolution of Ottawa Decision Support Framework*

### KEY ELEMENTS

- Primary Clinician Role to diagnose patient problem; discuss options; screen for decisional conflict; refer for support
- Goal is to achieve a quality decision that is defined as informed decision making based on patients’ priorities and values
- Patient Role to identify and communicate informed values and priorities shaped by their social circumstances
- Decision coach role to assess for factors influencing decision making, provide support to minimize decision-making needs, evaluate the quality of the decision and decision-making process and screen for barriers interfering with implementation of the decision. Coaches are health professionals trained in decision support and who are supportive but ‘relatively’ neutral in the decision (e.g. nurses, social workers, psychologists, genetic counselors)

Two assumptions: decision quality improves when patients and practitioners participate in decision making; decision coaching facilitates patient engagement and empowerment in shared decision making

### STRENGTHS

- Proposes an interprofessional approach to shared decision making
- Incorporates decision support into process of shared decision making
- Relevant to a variety of practice settings and situations where patients are involved in health decisions

### LIMITATIONS

- Not widely evaluated in clinical settings or research
- Broader environmental factors are not considered (e.g. political issues)
- Not as relevant for some decision situations (emergency situation; ethical and legal)
<table>
<thead>
<tr>
<th>PRACTICE THEORIES</th>
<th>KEY ELEMENTS</th>
<th>STRENGTHS</th>
<th>LIMITATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Framework for Basic Studies in Patients’ Decision Making (Llewellyn-Thomas, 1995)</td>
<td>■ Intrapersonal factors of the patient, physician, and family: demographic characteristics, health status of the patient, treatment processes, time, participation in decision making, information, expectations and preferences</td>
<td>■ Includes environmental influences (cultural and political) on patient involvement in decision making</td>
<td>■ Primarily focused on informing researchers</td>
</tr>
<tr>
<td></td>
<td>■ Interpersonal factors: decisional transaction that occurs between the patient, health care professional and family founded on intrapersonal factors based on transferring of information, motivations, and assumptions made about each other</td>
<td></td>
<td>■ A theoretical basis for the framework is not provided</td>
</tr>
<tr>
<td></td>
<td>■ Extra personal factors: institutional traditions, referral patterns, resources, constraints on the decision-making processes and intrapersonal factors</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>The assumption: these three interactive elements characterize decisions encountered by patients</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix J: Traditional Decisional Conflict Scale  
(O’Connor, A. M., 1995)

Note: Always precede the Decisional Conflict Scale with an option preference question, which is not included in scoring. [See item ‘A’ below].

My difficulty in making this choice

A. Which [insert treatment/screening] option do you prefer? Please check ✔ one:
- [Option 1]
- [Option 2]
- [Option 3]
- Unsure

B. Considering the option you prefer, please answer the following questions:

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>I know which options are available to me.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>I know the benefits of each option.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>I know the risks and side effects of each option.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>I am clear about which benefits matter most to me.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>I am clear about which risks and side effects matter most to me.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>I am clear about which is more important to me (the benefits or the risks and side effects).</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>I have enough support from others to make a choice.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>I am choosing without pressure from others.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>I have enough advice to make a choice.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>I am clear about the best choice for me.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>I feel sure about what to choose.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td>This decision is easy for me to make.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13.</td>
<td>I feel I have made an informed choice.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>My decision shows what is important to me.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>I expect to stick with my decision.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td>I am satisfied with my decision.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix K: Decision Coaching as a Nursing Intervention for Tailoring Patient Decision Support


Nurses can use decision coaching to meet patient decision-making needs. In decision coaching, the nurse brings knowledge of the clinical options, potential advantages and disadvantages linked to the options being considered, risk of side effects and resources that will be needed to implement the decision. The patient brings expertise about their situation and circumstances and personal knowledge about what is most important to achieve, or avoid, among the features of the options being considered. Figure 9 details the decision coach role.

Figure 9: Decision Coach Role

Primary clinician’s role
To diagnose the patient’s clinical needs, discuss options, screen for decisional and implementation difficulties and refer to a coach, if needed

Goal
Informed decision making based on clinical priorities and patient’s priorities and values

Patient’s role
To identify and communicate informed values and priorities shaped by their social circumstances

Coach’s role
To improve patient’s confidence and the skills needed to participate in his or her clinical care

Skills
Consultation preparation skills; raise questions and concerns; communicate and negotiate with health care team
Deliberation skills; clarify decisional needs (uncertainty, knowledge, values, support); use information; clarify and communicate values and priorities; access support and handle pressure
Implementation skills (motivational interviewing); increase motivation to change; strengthen self confidence; channel resistance to change; overcome barriers
Appendix L: Description of the Toolkit

Best practice guidelines can only be successfully implemented if there are: adequate planning, resources, organizational and administrative support as well as appropriate facilitation. In this light, RNAO, through a panel of nurses, researchers and administrators has developed the Toolkit: Implementation of Clinical Practice Guidelines based on available evidence, theoretical perspectives and consensus. The Toolkit is recommended for guiding the implementation of any clinical practice guideline in a health care organization.

The Toolkit provides step-by-step directions to individuals and groups involved in planning, coordinating, and facilitating the guideline implementation. Specifically, the Toolkit addresses the following key steps in implementing a guideline:

1. Identifying a well-developed, evidence-based clinical practice guideline.
2. Identification, assessment and engagement of stakeholders.
3. Assessment of environmental readiness for guideline implementation.
4. Identifying and planning evidence-based implementation strategies.
5. Planning and implementing evaluation.
6. Identifying and securing required resources for implementation.

Implementing guidelines in practice that result in successful practice changes and positive clinical impact is a complex undertaking. The Toolkit is one key resource for managing this process. The toolkit can be downloaded at www.rnao.org/bestpractices.
Decision Support for Adults Living with Chronic Kidney Disease

Made possible by the funding from the Ontario Ministry of Health and Long Term Care