



SDMC News & Notes Surrogate Decision-Making



NEWS & NOTES

THE "THIRD CHOICE" - Voting for More Information at a Hearing

It is the goal of the SDMC program staff to provide panel members with adequate information, in every case, to reach an informed, timely and person-centered decision on the date of the hearing. Testimony to this is that in the vast majority of cases, volunteer panels reach three concrete decisions on the date of the hearing: 1) does the patient have the capacity to make his/her own decision [clear and convincing standard]; 2) is there a legally authorized, willing and available surrogate [clear and convincing standard]; and 3) is the proposed medical treatment in the best interest of the individual [fair preponderance of the evidence standard].

There are times, however, when panel members require additional information regarding capacity, surrogacy, or best interest before making a determination. The panel's first duty is to review the paperwork in advance (if possible) and request additional information from the SDMC nurse listed on the cover of the case. SDMC staff will attempt to provide the requested information to you, the other panel members, and the listed interested parties, prior to the hearing.

Panel members should consider both the documentary evidence and testimony of providers in reaching a decision. Some times the documents in your case packet alone support the proposed care and treatment when the testimony provided is not as supportive as it could be and vice versa. Remember, you may rely on either the documents in the case packet or the testimony to support your determination. A well prepared 220-A form and additional consults provide the panel with indication of the MD's intent and discussion of risks, benefits and alternatives to the proposed medical treatment, as well as the potential outcome with and without the treatment. The CQCAPD supplemental information we send with each case also provides the panel with similar information.

Requests for additional information at the hearing should be seeking NEW INFORMATION NOT OTHERWISE AVAILABLE IN THE CASE PAPERWORK OR PROVIDED IN THE TESTIMONY.

The panel should attempt to obtain additional information or clarifications before voting. You should ask the SDMC/CQCAPD representative who is at the hearing to call the person who may have the information you need and after the chair has sworn them in, they may answer the panel's questions – ideally by speaker phone, if available.

When you cannot reach the physician who completed the 220-A or another physician or professional in their practice, consider obtaining testimony about the proposed treatment from another person, e.g., nurse, the facility medical director or primary care physician.

If the panel has made a reasonable effort to secure additional information while still at the hearing and that effort has not resulted in sufficient information to make a decision (e.g., no medical personnel available to answer a question); the panel may "Vote More Info" on that question.



NYS Commission on Quality of Care & Advocacy for Persons with Disabilities
401 State Street
Schenectady, NY 12305
1-800-624-4143 (Voice/TTY/Spanish)



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First, however, the panel must apply the correct legal standard concerning best interest. In order to consent to the proposed treatment, the panel must decide by a fair preponderance of the evidence that the proposed treatment is in the individual's best interest. A fair preponderance of the evidence traditionally means that the evidence, when weighted for its quality rather than quantity, tips the scale in favor of treatment. Applying a higher clear and convincing standard of evidence can result in unwarranted delays in care and treatment.

Additionally, if there is a known procedure date and the request for NEW INFORMATION will likely delay the treatment the panel should weigh the importance of their request for additional information against the risks to the health of the patient by delaying the treatment until the new information can be obtained and reviewed.

If at least three panel members "Vote More Info," on any of the three issues, all panel members should hold onto their case packets and put them in a secure place so that the original information will be available to them at the time of the conference call. Keep in mind that if the panel does "Vote More Info" on capacity, no vote should be recorded on the remaining two issues. And should the panel "Vote More Info" on surrogacy, no vote should be recorded on best interest.

At the conclusion of the hearing, the panel, with the assistance of the SDMC representative, should complete CQCAPD Form-14, to clearly communicate what NEW INFORMATION is needed for them to reach a decision. If the panel cannot isolate and articulate their request, there is a strong possibility that the panel already has all the information it needs to make a decision.

The panel members should discuss possible dates to reconvene via conference call. The date(s) to reconvene should generally be within two to three weeks from the original hearing to allow time for the provider to obtain the additional information requested and for SDMC staff to disseminate this information to all interested parties. Shorter times should be considered as the care needs of the patient dictate. By agreeing on a date to reconvene and forwarding this information to SDMC staff, panelists will:

- 1) have more time to arrange their schedules to accommodate the conference call;
- 2) minimize the time spent away from their normal day to day duties caused by the number of phone calls or mailings they receive from SDMC staff to coordinate a conference call date; and
- 3) ultimately make a determination in a more timely fashion.

After the hearing, the SDMC/CQCAPD representative will send CQCAPD Form-14 to SDMC staff (usually Noreen Haupt) who will work with the Declarant to obtain the needed information, get it to the panel in a timely manner and set up a mutually convenient time for a conference call.



OTHER REASONS FOR CONFERENCE CALLS

A conference call can also be requested by the Declarant if the medical care which was originally approved at a hearing was not obtained prior to the expiration of the consent period. An example of this would be when the patient had a cold or other medical condition that prevented him/her from keeping his/her appointment. Rescheduling the appointment may take some time. A review of the patient's record, plus testimony from the Declarant on a conference call, can provide the patient with a timely and cost-effective method to extend the period of consent and get the treatment he/she needs.

Conference call proceedings can also promote more timely and consistent care when used to review related medical care. Panel members can reach decisions based on their knowledge of the care and treatment history of the person, in addition to the supplemental medical information for the related medical procedure.

Another reason for a conference call would be to provide information concerning any changed circumstances, new conditions or information. An example of this would be if the panel had voted that the procedure was not in the best interest of the person. Now, however, there is new information for the panel to consider, and after such consideration, the panel can modify their original decision.

Finally, a conference call may be used when it appears to be more appropriate to meet the needs of the individual for timely decision-making as determined by the circumstances. An example would be an expedited case.

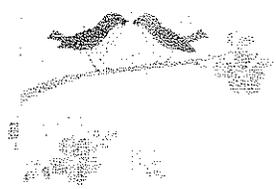
Mileage Reimbursement

REMINDER: Mileage will be reimbursed at different rates depending on your Dispute Center. Check with your Dispute Center beforehand to verify their reimbursement rate.

Volunteers don't get paid, not because they're worthless, but because they're priceless. ~ Sherry Anderson

FOCUS

By Patricia W. Johnson, Esq.



SDMC panel members have been given their mission right in the SDMC law: answer three questions.

1. Does the person have capacity? If not,
2. Does the person have an authorized surrogate? If not,
3. Is the treatment in the person's best interests or not?

Your job is to answer these questions in that order in a timely way to promote autonomy and the best interests of the person. If the hearing discussion and questions to the witnesses and patient take a detour to questions that will not address the answers to your mission in that order, you need to courteously aid the chairperson and get the hearing back on track in order to assure quality and timely decision-making on behalf of the person. Some examples of prolonged or delayed hearings:

Questions were asked regarding the patient's unrelated condition of cold hands. Once you confirm that this is not related to the major medical treatment being proposed - move on.

Questions regarding the validity of a health care agent were asked. Once a legal issue develops at the hearing contact SDMC Legal staff - Pat Johnson, and if I am unavailable, SDMC Program staff for matters of a legal nature. If necessary, additional information can be provided after the hearing testimony is obtained. In this case, the health care agent was unavailable due to an objection by the patient.

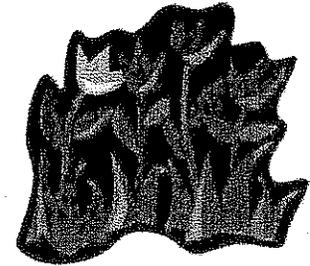
Questions were asked by the provider regarding related procedures (lab tests) that had been crossed out by the SDMC Program staff. Answer the three questions above and advise the provider to contact SDMC Legal staff. In this case the provider was advised that these related procedures were covered by the SDMC consent, if given, and that informed consent is generally not required for routine care.

Questions were asked about the person's individual services plan (ISP). If there is a concern or question of neglect or abuse, refer the concern to the SDMC program staff for follow up or referral as appropriate.

If you still have questions after you have heard the testimony on the three questions, you may ask for NEW INFORMATION (see earlier article in this newsletter).

Similarly, when you receive and review your case packet, if you are concerned that you may have a conflict of interest, contact Tom Fisher (518-388-2821) or Pat Johnson (518-388-1272) at SDMC for further assistance.

Thank you for your extraordinary service on behalf of New York State residents.



CAPACITY OR INCAPACITY?

While the first question that the SDMC panel must decide – “Does the patient have capacity?” - may not appear complex initially, it is an essential and important task not to be taken lightly. Since New York State provides for a presumption of capacity, the panel must explore the question of the person’s ability to decide on his or her own behalf in detail in order to demonstrate the person’s clear and convincing incapacity before proceeding to the next question.

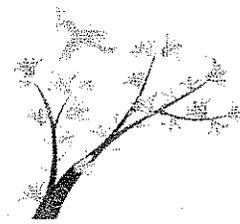
To explore this issue further, one should note that decision-making capacity is specific to each particular decision. Although some people lack this capacity for all decisions, many are incapacitated in more limited ways and may be capable of making some decisions (blue or red shirt) but not others (dental procedure or not). The presence or absence of capacity does not depend on a person’s particular diagnosis/disability or on the opinion they offer, but on that individual’s actual functioning in the situation in which the decision about health care is to be made.

Article 80 of the Mental Hygiene Law governing the SDMC, MHL §80.07(e), authorizes the review of the person’s capacity for the specific proposal of major medical treatment/s. The issue of capacity means whether or not the person adequately understands and appreciates the nature and consequences of a proposed major medical treatment, including the benefits and risks of and alternatives to such treatment, and the person cannot reach an informed decision to consent or refuse such treatment in a knowing and voluntary manner that promotes the patient’s well-being.

The SDMC regulations further describe your considerations for the capacity review in 14 NYCRR §710.4(d) (2) and these can be found both in your SDMC handbook at Memorandum 3 and below:

[T]he panel shall consider whether the patient is unable to adequately understand and appreciate the nature and consequences of the proposed major medical procedure, including:

1. the burdens of the treatment to him or herself in terms of pain and suffering outweighing the benefits, or whether the proposed treatment would merely prolong his or her suffering and not provide any net benefit to him or her;
2. the degree, expected duration and constancy of pain with and without treatment and the possibility that his or her pain could be mitigated by less intrusive forms of medical treatment, including the administration of medications;
3. the likely prognosis for him or herself, expectant level of functioning, degree of humiliation and dependency with or without the proposed major medical treatment; and
4. his or her ability to evaluate treatment options, including non-treatment and their benefits and risks compared to those of the proposed major medical treatment.



CAPACITY OR INCAPACITY? (CONT'D)

Questions to assist you in obtaining additional information at the hearing with regard to the person's capacity are available at the end of SDMC Handbook Memorandum 6. Additional suggested questions are taken primarily from Dr. Appelbaum (see bibliography) and are listed below.

It's important to remember that sample questions are intended to provide guidance and not all questions will be applicable to every SDMC proceeding. Panel members should use their judgment to determine what additional questions should be asked in a particular case. Remember to word your questions in a manner appropriate for the individual and to address them first before asking questions of the provider staff. Assistance can always be obtained from the SDMC Program and Legal Staff by calling the CQCAPD before or during the hearing.

For the person:

- What is your name? How old are you? Where do you live?
- Do you know why you are here today? Have you been to see a doctor?
- Has the medical procedure been explained to you?
- Do you feel pain?
- Have you decided whether to have the procedure or not?
- Please tell me in your own words what the doctor wants to do?
- What does the doctor say is the problem with your health?
- What does the doctor say will happen to you if you have the procedure? And, if you do not have the procedure? Is there an alternative or different procedure that the doctor decided not to do?
- Did the doctor explain the risks and benefits of the treatment?
- What are the risks? What are the benefits?
- What do you think is wrong with your health now?
- Do you believe you need some kind of treatment?
- What is treatment likely to do for you?
- What makes you think it will do that?
- What do you think will happen if you are not treated?
- Why do you think the doctor wants you to have this treatment?
- How did you decide to accept or reject this treatment?
- What makes [person's choice] better than [doctor's choice]?

For Staff, Correspondents, and Other health care professionals:

- Do you think the person understands what the doctors are going to do?
- Does the person understand how the treatment will help him or her?
- Does the patient understand the degree of pain and suffering that s/he will experience with or without treatment?
- Does s/he understand whether there are other treatment options, including non-treatment?
- Does the patient understand the nature and consequences of those treatment options?

CAPACITY OR INCAPACITY? (CONT'D)

Resources:

President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. "Making health care decisions: a report on the ethical and legal implications of informed consent in the patient-practitioner relationship" Vol. 1. Washington, DC: Government Printing Office, 1982. http://bioethics.georgetown.edu/pche/reports/past_commissions/making_health_care_decisions.pdf

New England Journal of Medicine, 2007; 357:1834-40 "Assessment of Patients' Competence to Consent to Treatment" Paul S. Appelbaum, M.D. <http://content.nejm.org/cgi/reprint/357/18/1834.pdf>



UPDATING YOUR CONTACT INFORMATION

Volunteers are vital to the success of the SDMC Program. When you have a change in mailing address, home phone/fax, work phone/fax, cell phone, place of employment or dates/times/counties of service, please notify Beth Rogers by email at:

beth.rogers@cqcaped.state.ny.us

or regular mail at:

Beth Rogers
NYS CQCAPD
SDMC Program
401 State Street
Schenectady, NY 12305.

Fell free to call us with your questions, concerns or comments at 518-388-2820. We are always available to help!

Those who can, do. Those who can do more, volunteer. ~ Author Unknown



How to Handle Objections

Patricia Johnson, CQCAPD Assistant Counsel, SDMC Program

The Surrogate Decision Making Committee (SDMC) Program is a quasi-judicial process and, as such, the SDMC hearing Chairperson and Panel Members are afforded a measure of discretion in their efforts to assure that the SDMC hearing is conducted in a fair manner. The following suggestions may enhance the process, assuring timely decisions in the best interest of those we serve.

- ❄ The Chair and the Panel need to ensure they are, and are regarded, as impartial decision-makers, so that individuals involved in the process and the public have confidence the system meets its legislative goals. These goals include: timely access to health care for people with mental disability; respect for personal autonomy of the individual with capacity; and, health care decisions for persons without capacity that are based on the best interests of the person and reflect, to the extent possible, the person's own beliefs and values. [Mental Hygiene Law §80.01]
- ❄ SDMC Article 80 does not require conformity with the formal rules of evidence. [MHL §80.07(d)] Accordingly, the Panel may receive objections and should note them and any offered evidence in the record, but need not rule on them. For example, the Chair may state, "Your comments are noted for the record. Let's proceed." It is up to the Panel to decide the weight that should be given to the objection or offered evidence. The Panel should not concern itself with whether MHLS or another party will appeal the Panel's determination but, rather, whether or not to sustain the objection; that is, whether to agree with and to put into effect MHLS' or any party's suggestion.
- ❄ The Panel Chairperson should conduct the hearing in a manner which is firm and deliberate to ensure that the hearing runs smoothly. If necessary, the Chairperson should call the Commission Program and Legal Staff for assistance so that the hearing is conducted in a temperate, dignified and professional manner, with each party getting the opportunity to be fairly heard and present relevant evidence. Panel Members should avoid arguing among themselves in the open hearing. Any disagreements among Panelists can be addressed in deliberations and with consultation with Commission Program or Legal Staff. The hearing can be reopened, if necessary, or the issue determined on appeal. The Panel is not required to explain rulings, objections, or determinations. However, the Panel's demeanor should clearly reflect their willingness to consider objectively all of the evidence which comes before them. As such, Members should carefully read the documentary evidence and listen to the testimony, get consultation from Commission Program or Legal Staff and render a reasoned decision.
- ❄ To maintain control of the hearing, the Panel Chairperson may place reasonable time limits on the presentation of evidence or statements. As soon as the subject under inquiry is exhausted or fully developed, you may stop the party or the witness and direct him or her to go to other matters. If the question or answer is redundant or irrelevant or improper, you may move on without waiting for the answer. You set the tone of the hearing through use of calm authority. You should not engage in arguments with the parties or witness, but should listen to objections made, note them in the record, and then move on.
- ❄ The record is your friend and the Panel Chairperson should control it. Ultimately, the record can substantiate a Panel's determinations on appeal, if necessary. Parties may go off the record if the Chair and the Panel is in agreement, for instance, if a break is required or the Patient is being excused; however, you need to keep all discussion regarding the case other than deliberations on the record. This gives the appearance of, and assists the Panel in, conducting an impartial hearing. The record is required to include all the evidence in support of your determinations. Thus, you must also refrain from private conversations before and after the hearing with the parties. You may speak with SDMC Program and Legal Staff to get any information or assistance you need but the SDMC Panel is the decision-maker, the quasi-judicial body.



How to Handle Objections (Continued)

Patricia Johnson, CQCAPD Assistant Counsel, SDMC Program

- * During the hearing, do not have more than one person speak at a time; identify all parties who are speaking before or after they speak unless they self identify; and clarify inaudible statements such as "un huh" and "nuh uh" and gestures with "Let the record reflect that..." As Panel Chair, let the parties know they are to address comments to you and the Panel and not to others unless they are questioning a witness.
- * Clarify the documentary evidence before or at the hearing if there are blank pages or indecipherable information. Let the SDMC Program Nurse who prepared the case know if there are any problems so that she can rectify them before the hearing if possible.
- * MHLS is the representative of the Patient and owes a duty of loyalty to the Patient to assert Legal rights or to make objections on the person's behalf. The Commission's Legal Services Bureau is available to assist the SDMC Panel to address the issues to be determined in regard to the person's care and right to have informed consent under the New York Public Health Law for any major medical treatment. The MHLS Attorney does not represent the facility and is not counsel to the Panel.
- * Communicate clearly and calmly and require the same from the MHLS and other parties so that justice can be served and dignity maintained.

For more information on this topic, please see SDMC Memorandum 5 SDMC PANELS' TREATMENT OF OBJECTIONS DURING HEARINGS. Thank you for your service.

