

Information and Privacy Commissioner,
Ontario, Canada



Commissaire à l'information et à la protection de la vie privée,
Ontario, Canada

PHIPA DECISION 22

Complaint HA14-89

Erie St. Clair CCAC - Chatham

January 8, 2016

Summary: The complainant sought disclosure of the personal health information of her deceased mother, without the consent of the estate trustees, relying on section 38(4)(b)(ii) of *PHIPA* (information about the circumstances of death). In this decision the IPC finds that in refusing disclosure, the CCAC did not properly exercise its discretion under that provision and orders it to re-exercise its discretion. The complainant asked the IPC to order disclosure of the same information to her under section 38(4)(c), for health care purposes, and the IPC directs the CCAC to consider her request.

Statutes considered: *Personal Health Information Protection Act, 2004*, sections 38(4)(b)(ii) and 38(4)(c).

Cases Considered: PHIPA Decision 19.

INTRODUCTION

[1] This case concerns a request by an individual for the personal health information of a deceased family member, the obligations of a health information custodian under the *Personal Health Information Protection Act, 2004* (*PHIPA* or the *Act*) in considering a request for disclosure of such information, and the role of the Information and Privacy Commissioner of Ontario (the IPC or this office) in inquiring into the custodian's response to such a request.

BACKGROUND

[2] Section 38(4) of the Act permits a health information custodian to disclose the personal health information of a deceased individual in certain circumstances, including the following:

A health information custodian may disclose personal health information about an individual who is deceased, or is reasonably suspected to be deceased,

....

(b) for the purpose of informing any person whom it is reasonable to inform in the circumstances of,

(i) the fact that the individual is deceased or reasonably suspected to be deceased, and

(ii) the circumstances of death, where appropriate; or

(c) to the spouse, partner, sibling or child of the individual if the recipients of the information reasonably require the information to make decisions about their own health care or their children's health care.

[3] The complainant in this case made a request to Erie St. Clair Community Care Access Centre - Chatham (the "CCAC" or "custodian") for a copy of her deceased mother's health records for the last 7 months of her life. During this period, her late mother received health care from the CCAC. In her request to the CCAC, the complainant stated that her brother and sister are co-executors of her mother's estate and indicates that they have not given consent for her to obtain a copy of the records. The complainant cited compassionate reasons for disclosure, stating that she believes that coping with grief is an appropriate reason to permit disclosure. As well, she stated that it is not a violation of privacy as her late mother listed the complainant as a contact with the CCAC.

[4] The CCAC refused the complainant's request, indicating that she did not meet the requirements of *PHIPA*. The complainant complained to this office about the refusal to release the records to her.

[5] The IPC assigned a mediator to explore a resolution of the complaint. As no resolution was possible, it was forwarded to the adjudication stage of the IPC's processes. I decided to initiate a review of the complaint during which I sought and received written submissions from the complainant and the CCAC.

[6] On this date, I am issuing this and three other decisions relating to disclosure

under section 38(4).

DISCUSSION

[7] Unlike the *Freedom of Information and Protection of Privacy Act (FIPPA)* and its municipal equivalent, *PHIPA* does not provide a general right of access to information held by the organizations to which it applies. The only right of access established under *PHIPA* is the right, under section 52(1), of individuals to obtain access to records of their own personal health information.

[8] *PHIPA* draws a distinction between the provision of “access” to personal health information, and the “disclosure” of personal health information by a health information custodian. Individuals have a right of access to records of personal health information about themselves in the custody or control of health information custodians, subject to limited and specific exceptions. An individual’s right of access under section 52(1) of *PHIPA* must be exercised by the individual about whom the records relate or (if applicable) that person’s lawfully authorized substitute decision-maker on his or behalf.¹ The health information custodian is obliged to respond to the request for access and, if no exceptions apply, provide access.

[9] On death, the right of access may only be exercised by the estate trustee or, in the absence of an estate trustee, the person who has assumed responsibility for the administration of the deceased’s estate.² In this case, the complainant is not the estate trustee for her late mother’s estate, and she is therefore not entitled to request access under section 52(1) of *PHIPA*.

[10] In addition to the provisions of *PHIPA* governing “access” to records of personal health information, *PHIPA* contains provisions governing when health information custodians may “disclose” personal health information. Under *PHIPA*, disclosure is permitted with the individual’s consent or the consent of the individual’s substitute decision-maker (where applicable). In the case of a deceased individual, only the estate trustee (or, if there is no estate trustee, the person who has assumed responsibility for the administration of the deceased’s estate) may give consent. Disclosure without consent is also permitted, and in some cases required, under specific provisions in the *Act*.³

¹ Section 25(1).

² See section 5(1), defining “substitute decision-maker” and paragraph 4 of section 23(1), regarding deceased individuals.

³ Section 29.

[11] Since the estate trustees have not consented to disclosure of the personal health information to the complainant, the issue before me is whether *PHIPA* permits disclosure without their consent. In the circumstances of this case, the complainant believes she qualifies for disclosure without consent under sections 38(4)(b)(ii) and (c), set out above.

[12] This case raises issues about the obligations of a health information custodian when deciding whether or not to disclose information under these parts of section 38(4), the rights of individuals to complain to the IPC about a custodian's decision to not disclose information to them under this section, and the extent of the IPC's authority to inquire into such a complaint.

Representations

[13] In her complaint, the complainant states that she realizes that her late mother's health records are protected under *PHIPA*. However, she refers to section 14(4)(c) of the *Freedom of Information and Protection of Privacy Act*, which permits disclosure of personal information about a deceased individual to family members for compassionate reasons. She submits that *PHIPA* should be interpreted to include compassionate reasons for disclosure.

[14] The complainant relies on this office's PHIPA Fact Sheet 15, which states, among other things:

There may be circumstances in which a person may wish to obtain the personal health information of a deceased relative...There may be many reasons why obtaining such information is important to the surviving relative. For example, it may assist him or her in administering the deceased relative's estate, coping with the grieving process, or making knowledgeable decisions about his or her own health care or that of another relative.

[15] She states that she understands the need for privacy and protection of her late mother's health records. However, she feels that having access to them will help her find some closure and cope with her grief. She also states that her mother trusted her and listed her as one of her contacts with the CCAC. The complainant states that following her mother's death, she phoned an employee of the CCAC, who read some of the entries from her mother's health records to her. She states that the CCAC has already decided it is reasonable to verbally disclose portions of the records to her.

[16] Further, the complainant states that she believes there needs to be a precedent set for people in her situation who are either not able to contact the estate trustee, or not able to get consent. She submits that there are many families where siblings become estranged after a death, and there needs to be a provision supporting

disclosure of personal health records for compassionate reasons in *PHIPA*, just as there is in *FIPPA* (referring to section 21(4)(d) of that act).

[17] In her representations, the complainant submits that section 38(4)(b)(ii) applies because she is a person whom it is reasonable to inform of the circumstances of her mother's death. Before her death, her mother had listed her as a contact with the custodian. She states that her mother experienced a sudden and rapid deterioration of her health which started seven months before she died and it is appropriate to include those months as part of the "circumstances of death". She states that her sister, who was her mother's primary caregiver, did not give her adequate updates about her mother's circumstances.

[18] The complainant also submits that she qualifies for disclosure under section 38(4)(c). She submits that coping with grief can be a health care issue. Prolonged grief is included in the DSM-5 (Diagnostic and Statistical Manual of Mental Disorders, 5th Edition) and is therefore a medical condition. She states that she has sought counselling after her mother's death. She wishes to have an understanding of her mother's circumstances so that her mental health support team can guide her through the choices she can make to release her grief and move forward.

[19] The complainant also wishes me to consider section 24(1)(a)(ii) which lists factors that a substitute decision maker must take into consideration in giving or withholding consent to the collection, use and disclosure of an individual's personal health information. She believes that these factors should also apply to health information custodians. She states that, as her mother listed her as a contact, it was her wish for the complainant to have access to her personal health information and the custodian is not honouring that expressed wish.

[20] The complainant asks this office to uphold her mother's wishes and give her access to the personal health information she seeks. She made other submissions which I do not detail here but all of which I have considered.

[21] The CCAC states that the complainant requested a copy of the health record in order to "help me cope with my grief." It states that its interpretation of *PHIPA* is that it does not require or permit disclosure of personal health information to the complainant for that reason. While it has empathy for the concerns she identifies, it cannot disregard the legislation. Referring to section 23(1) of the *Act*, it states that its practice is to require consent from the estate trustee or person responsible for administering the estate.

Analysis

[22] There is no dispute that the information the complainant seeks is the "personal health information" of her deceased mother, within the meaning of the *Act*.

[23] Section 38(4) provides exceptions to the general rule requiring consent for the disclosure of personal health information. If the conditions of those exceptions are met, they permit a health information custodian to disclose personal health information about a deceased person, even without consent. The custodian may disclose information under section 38(4) verbally, or in a record. Where an individual claims to qualify for disclosure under section 38(4), the health information custodian must consider whether the individual meets the conditions for disclosure, and decide whether and how much information to disclose.

[24] In PHIPA Decision 19, I discuss the scheme of the *Act*, the duties of health information custodians in considering whether to disclose information under section 38(4)(c), and the role of the IPC in receiving complaints about a refusal to disclose information under that section. I adopt my findings in that Decision, and apply them here. Among other things, I stated that there is an "implied public statutory duty" that discretion under section 38(4)(c) be based on relevant considerations, and not be exercised in bad faith or for an improper purpose. I find that those principles also apply to the exercise of discretion under section 38(4)(b)(ii). It goes without saying that the duty also requires that the custodian turn its mind to the request for disclosure, and whether the person seeking the information meets the conditions permitting disclosure.

[25] In this case, I find that the CCAC failed to adequately consider whether any of the personal health information could be disclosed to the complainant under section 38(4)(b)(ii). Under this provision, a custodian is given discretion to decide when it is "appropriate" to disclose personal health information about the fact and circumstances of a death. Disclosures under this provision are not limited to family members, but it would be reasonable to expect family members to be included amongst those to whom disclosure may be appropriate. The CCAC seems to have taken the view that the complainant's reliance on compassionate reasons disqualified her from disclosure under any part of section 38(4). Under section 38(4)(b)(ii), however, a health care custodian may take into account a compassionate need for the information, in deciding whether and how much disclosure is "appropriate". I find that the CCAC should have considered whether disclosure of at least some information is "appropriate" under this provision.

[26] Based on the material before me, it appears that the CCAC gave the complainant some information about her mother's circumstances over the phone, following her mother's death. I do not know whether the CCAC was relying on section 38(4)(b)(ii) in providing her with this information. The complainant suggests that as the CCAC found it appropriate to provide her with verbal information, she should be granted access to the written records as well. I do not accept this submission. Even if the CCAC decided that it was permitted to provide some information verbally to the complainant, section 38(4)(b)(ii) does not oblige it to disclose records.

[27] In any event, the CCAC now takes the position that the complainant does not qualify for disclosure of any information under section 38(4)(b)(ii), and I find it has

failed to adequately consider the complainant's request. I will therefore direct it to consider the complainant's request again, and consider whether disclosure is permitted under section 38(4)(b)(ii). In doing so, I caution the complainant not to expect broad disclosure of her mother's records of personal health information. First, even if the custodian decides that it is appropriate to share some information, it is permitted to share the information verbally, without release of any records. Second, the disclosure is restricted to information about the "circumstances of death." While acknowledging the complainant's view that information about her mother's medical conditions in the 7 months leading to her death is all related to the "circumstances of death", I find it unlikely that section 38(4)(b)(ii) supports this breadth of disclosure.

[28] Third, it is clear from the wording of this provision that custodians have been given broad discretion. A custodian "may" disclose, "where appropriate". If the CCAC decides, based on relevant considerations, and in a good faith exercise of discretion, that none or only some of the personal health information of the complainant's mother should be disclosed to her for the purposes of this provision, it has met its statutory obligations.

[29] Fourth, as I explained in PHIPA Decision 19, the only power given to this office to order a custodian to provide access to a record is found in section 61(1)(a), in response to an individual's request for records of his or her own personal health information. This section does not provide the IPC with the authority to order disclosure of information in response to a complaint under section 38(4). However, if a custodian has exercised discretion improperly or based on an incorrect interpretation of the conditions for permitting disclosure, I can direct that the custodian review the matter again.

[30] In this case, as I have stated, I will direct the CCAC to consider the complainant's request for disclosure under section 38(4)(b)(ii). I will also direct it to provide me with its response to the complainant's request for disclosure under that provision, so that I may assess whether it exercised its discretion in accordance with its statutory duties.

[31] I now turn to section 38(4)(c). The complainant's request to the CCAC did not indicate that she was seeking disclosure for the purpose of her own health care. In this review, however, she has raised section 38(4)(c), and submitted information that she believes supports her need for the information, for the purpose set out in that section. Having regard to the scheme of the *Act*, I do not find it appropriate to decide whether disclosure to the complainant is permitted under section 38(4)(c), where no request has been made to the CCAC in the first instance. It is the CCAC's role and duty to consider such a request, having regard to the circumstances of the request and the personal health information in its files. The CCAC has not had the opportunity to consider whether to exercise its discretion to disclose information to the complainant under section 38(4)(c), and I therefore direct the complainant to make her request for disclosure to the CCAC.

[32] Further, I recommend that the complainant's request be accompanied by a statement from a health care practitioner describing what kind of information is sought, and why that information is required by her in order to make decisions about her health care. Although a complainant is not required to make a request for disclosure under section 38(4)(c) through a health care practitioner nor provide evidence from a health care practitioner supporting the need for the information, this supporting documentation will help her to show that the conditions permitting disclosure under section 38(4)(c) exist. As disclosure under section 38(4)(c) must be based on a health care need, a health care practitioner is in a position to provide the best evidence of that need.

[33] Again, in responding to her request, the CCAC has a duty to consider the request in good faith, for no improper purposes, and taking into account relevant factors. As above, I will direct the CCAC to provide me with its response to the complainant's request for disclosure under section 38(4)(c), so that I may assess whether it exercised its discretion in accordance with its statutory duties.

[34] In arriving at my conclusions above, I have considered all of the complainant's representations even if I have not explicitly addressed them. For her benefit, I will indicate that I do not accept her submission that her mother gave express consent to disclosure of information to her when she listed the complainant, before her death, as a "contact" person. Whether or not this amounted to consent to disclosure of personal health information to the complainant before her mother's death, *PHIPA* explicitly addresses consent requirements following a death. Under the scheme of the *Act*, upon her mother's death, the estate trustees assumed the authority to give or withhold consent.

ORDER:

1. For the foregoing reasons, I order the CCAC to consider the complainant's request for disclosure under section 38(4)(b)(ii).
2. I order the CCAC to consider the complainant's request for disclosure under section 38(4)(c), taking into account any additional information the complainant provides to the CCAC.
3. I direct the CCAC to provide me with its response to the request and its reasons for disclosing or not disclosing the personal health information of the deceased to the complainant, whether verbally or in a record. This response shall be forwarded to my attention, within two weeks of the submission of any additional information from the complainant or, if she chooses not to submit any additional information, the date she informs the CCAC of this.

Original Signed by: _____
Sherry Liang
Assistant Commissioner

_____ January 8, 2016