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Health issues in prospective members

- How to evaluate candidates with chronic health issues** 3
by Myles N. Sheehan, SJ, M.D.
- Ethical issues raised by candidates with health concerns** 8
by Thomas N. Nairn, OFM and Dawn Nothwehr, OSF
- Living religious life with chronic illness** 13
by Mary Therese Johnson, OP
- What canon law says about health concerns in prospective members** 17
by Eileen C. Jaramillo
- Developing admissions policies regarding HIV** 20
by Jon Fuller, SJ, M.D.
- How MS or epilepsy could affect a candidate to religious life** 28
HORIZON interviews Daniel R. Wynn, M.D. and Cathy Meyer, R.N.
- Mobility issues in prospective members of a religious community** 31
by Louis Lussier, OSCam, M.D.
- Chronic back pain and the capacity to live religious life** 35
by Daniel Hurley, M.D.
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Welcome to the gray zone

Not much about vocation ministry is black and white. And sorting through the practical, ethical and spiritual issues of candidates with health complications puts vocation ministers squarely into gray area. Life would be much simpler if communities could simply consult a list of health conditions that are permitted or not permitted: “We’ll take applicants with Diseases A, B or C. But we can’t accept anybody with Diseases X, Y or Z.”

That would be easier, but it wouldn’t be fair to either candidates or communities. A simplistic approach that is quick to exclude leaves behind candidates who are coping well with their diagnoses and who, perhaps with a little extra effort, could contribute greatly to a community and its mission. The candidates lose by not being able to fully live their vocations. The communities lose by not gaining the energy and life of new members.

On the other hand (it’s not simple, remember?), if communities are too quick to include people with chronic health conditions, they could run into health expenses they cannot afford. They may find the person quickly becomes unable to minister or take care of basic needs. The effort to accommodate and care for a physically weak new member could drain energy and resources away from caring for frail elderly members.

The writers for this edition acknowledge that vocation ministers are operating in a gray zone when it comes to candidates with health problems. Our writers encourage vocation ministers not to devise a list but, rather, to assess each individual on a case-by-case basis. How is the person coping right now? What is the long-term prognosis? Can he or she live in and contribute to the community? To the mission? How much accommodation does the community need to make? How much expense or accommodation is too much?

Our articles reflect on these questions and more. They also provide practical medical information about several common chronic health issues. (This edition strictly looks at physical health concerns; see the Spring 2005 edition for an examination of mental health concerns.)

So if you find yourself in a gray zone over a candidate with health concerns—or want to prepare for it—read on. And may the Spirit provide you with the wisdom needed for living in a world that is rarely black and white.

—*Carol Schuck Scheiber, Editor*

When assessing a candidate with chronic health issues, vocation ministers must take into account the impact of the condition or illness, feedback from health professionals, and the particulars of their congregation.

How to evaluate candidates with chronic health issues

by Myles N. Sheehan, SJ, M.D.

Evaluating a candidate's suitability for religious life in a particular congregation can require considerable reflection and evaluation. This is especially true when the candidate has a chronic health condition. What are some guidelines to assist vocation directors and other decision-makers considering such a candidate? As both a physician and a Jesuit priest, I can provide some suggestions and rules of thumb. But these suggestions depend much on the candidate, the exact details of the chronic illness evaluated in a holistic perspective, and the charism and resources of the congregation.

I suggest three questions to provide a framework for considering the suitability of a candidate with a chronic physical health condition:

- What is the impact of the condition?
- What is the assessment of health care professionals?
- Does the candidate make sense for your community?

Assessing the impact of the health issue

I'll begin with the first question regarding the effect of a particular illness or diagnosis upon the candidate. This question has several facets, beginning with a diagnosis. Many individuals carry around a diagnosis of an illness, but they are doing well. It is important that

vocation directors not reject simply on the basis of the candidate's report of a diagnosis. That report should be the start of a conversation. As an example, a candidate may have been told that she has rheumatoid arthritis. This disease can vary from debilitating and life threatening to a relatively easily-controlled condition that rarely flares up. It would not be sensible to admit into religious life someone who is seriously ill with a poor prognosis. But another individual could have the same diagnosis and live without any real problems. You can avoid arbitrary decisions by recognizing that a diagnosis may not tell you much and that you need to dig a bit deeper.

Second, individuals with a chronic illness may have limitations in function. Specific understanding of how the illness affects the individual's functional abilities is crucial in determining the suitability, or difficulty, of a person's entry into a religious community. Is the person able to take care of the most basic activities of daily living? Can he or she get in and out of bed without assistance, shower or bathe, use the toilet, get dressed, take care of basic personal grooming, and feed himself or herself? A deficit in one of these six activities of daily living is a sign that a person cannot live independently and needs either a home health aide or care in an institutional setting.

There are other tasks crucial for independent functioning. These are called instrumental activities of daily living. There is no simple list for instrumental activities. These are the tasks that allow us to interact and be independent in the larger community. They include managing one's checkbook and financial resources, using transportation, shopping for household supplies and groceries, keeping an apartment clean, preparing food, doing laundry and the like. Many individuals (particularly some men who are otherwise without a

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diagnosis of chronic illness!) might have an isolated deficit—some people don't cook; others don't drive; some people are sloppy about cleaning. But when a person has multiple deficits, it requires a lot of effort to keep that individual safe and otherwise healthy. When a person with chronic illness is losing the ability to perform these activities of daily living, it is a sign that the illness is progressing and taking a larger toll. Deficits in activities of daily living or a progressive loss of ability to perform the instrumental activities of daily living indicate an individual needs substantial assistance.

Candidates who seem overly involved and identified with their illness, whose lives and personality are filled with excessive drama and conflict, are likely not going to be happy in religious life and may well make life miserable for those with whom they live.

Attitude and approach to the illness

It is also crucial to evaluate the impact of the illness on the person and those around that person. This involves thinking about how the illness influences the person psychologically, in social interactions and in community. It requires consideration of how the illness is part of the person's spiritual life. Some people with what appear to be minor health conditions can be completely absorbed in the illness, be wrapped up in visiting a variety of physicians and other caregivers and be a general pain in the neck to be around. The illness is the focus of the person's life, monopolizing conversation and creating a situation that limits the freedom of the individual to pray and work. When illness is the focus, it also creates difficulties for those who live with him or her.

Conversely some individuals with serious health conditions—for example, a complicated case of diabetes—are exemplary in taking prudent control of their illness, occasionally need a hand when there is a problem (an episode of low or high blood sugar), and deal well and courageously with the possibility of more se-

rious problems down the road (people with diabetes are at higher risk for vascular, vision, and kidney problems than those without). This type of person may well need to make regular visits to the physician. He or she sometimes gets anxious about a problem related to the diabetes and recognizes that his or her prayer may often refer to hopes and fears related to the illness. These features would suggest a realistic integration of a problem.

But candidates who seem overly involved and identified with their illness, whose lives and personality are filled with excessive drama and conflict, are likely not going to be happy in religious life and may well make life miserable for those with whom they live. Vocation directors would do well to exercise caution with the candidate who appears to have a variety of caregivers seen with great frequency and with multiple emergencies, who continually feels poorly, and whose conversation, energy, and probably prayer all revolve around his or her condition. Religious life always involves giving something up; it may well be that giving up being sick is too much for some individuals. If the person's identity revolves around a medical diagnosis, either because of the person's personality or the severity of the illness, then it will be difficult for that person to be integrated into religious life.

Finally, in seeking to understand the impact of a health condition on a candidate, I suggest that the vocation director look at some basic facts. *How old is the individual?* An older person with a chronic illness who is beginning to have increasing difficulty is not likely going to be able to do as much apostolic work as a young person who has a potentially disabling chronic illness but who is currently active, independent and doing well. *How much does the illness cost the person daily in money and time?* A person may have an illness or a diagnosis that requires a variety of medications that are extremely expensive and demand careful monitoring and a rigorous schedule. Again, this type of regimen could be tough when the focus is supposed to be on apostolic life. *What is the prognosis of the illness?* There are a lot of reasons why people may consider religious life. Having a life-threatening illness often makes people want to square things away with God and, for some, that might mean making a dramatic move into religious life. I would not question that God may well be working with a person who has a fatal illness who seeks religious life. I would be very cautious and likely fairly skeptical that God is calling that person

to religious life. Instead I would work with that person to assist in discerning God's call in such an emotionally charged time.

Listening to health professionals

The second main question for a candidate with a chronic health issue is: what is the assessment of health care professionals? The vocation director can only do a certain amount of assessment personally. In eliciting assessment of a candidate, there are three points to consider.

First make sure you have a physician that you or your congregation trusts to make an initial assessment and determine what further assessment may be needed

Psychological assessment is important for individuals with chronic health issues, not because they are more likely to be mentally ill, but because it is essential that the community know about coping styles, areas of vulnerability, and response to stress and adversity.

medically. I would not rely on the evaluation of the candidate's physician as the only assessment. The person's physician likely will provide valuable insight and essential details of the medical facts of the person's condition and history. But it is unlikely that the candidate's physician will understand much about religious life, much less the particular details of a congregation, in order to give the advice and insight that a physician known and trusted by the congregation can give. It could be that the doctor may want to help the patient in his or her goal and may present a somewhat more optimistic picture than a less biased observer.

I suggest that a general assessment be done by an internist or family practitioner who is known to the vocation director and who has a realistic sense of the congregation. That general evaluation may well require follow-up and a visit to a specialist in order to provide a fuller picture. Determining a prognosis for a person who is currently stable, particularly one that in-

volves a disability, is not always straightforward for a primary care physician. Evaluation by an expert in rehabilitation medicine (also known as a physiatrist) may help determine the possibility of increasing disability, whether the person might need adaptive equipment, and what type of work the person could sustain. Other individuals could require assessment by specialists in arthritis (rheumatologist) or neurology. For a candidate who seems promising, that type of careful evaluation is crucial in making sure there is true freedom on both sides before committing to a formation program.

In proceeding with this type of assessment, the vocation director must be very clear with the candidate about the sharing of medical information. If the religious order arranges for an assessment, the results of that assessment need to be shared with the vocation director and others who would decide about admission to the novitiate. The candidate will need to sign a release with the physician doing the evaluation to allow him or her to share information about the visit with the vocation director and the director's colleagues. Generally it is not appropriate for the vocation director to share this type of personal health information with the community. But the candidate needs to understand that confidential details about one's health history must be shared with those in a congregation who decide on admissions.

Second it is important that skilled psychological assessment be performed as part of the determination of suitability for religious life. This is increasingly true for any candidate. It is even more important for individuals with chronic health issues, not because they are more likely to be mentally ill, but because it is essential that the community know about coping styles, areas of vulnerability, and response to stress and adversity. An individual who is physically robust but psychologically unstable does not make a good candidate for religious life. This is true, *a fortiori*, if the person has serious physical health problems.

The third point to think about is the physical environment of the formation community in which the candidate would live. If you are going to accept a bright, gifted, and mature young man who is wheelchair-bound into your community, you better be sure, at a minimum, that the novitiate is wheelchair accessible, that he will have a bed that allows him to pull himself up and out in the morning, that there is an adequate toilet and shower facility, and, in the event of a fire or some other emergency, there is a reasonable escape

route. How do you get such an assessment? It depends on the resources in your area. As a start you could contact a local rehabilitation hospital and ask for a referral for a home assessment. A therapist skilled in matching the needs of an individual to the home environment can help provide advice.

Be cautious in making too many allowances for a candidate's physical condition if your charism emphasizes activity, independence and vigorous apostolic commitment.

Does the candidate make sense for your community?

All of these considerations lead to the third main question of this article: what type of candidate makes sense for your community? This depends on your order's charism, the expression of that charism in its rule or constitutions, the reality of the community's resources (personal, financial and physical) and the presence of other gifts in the candidate that could make accepting an individual with some problems a worthwhile decision. The issue here is not so much the possibility for ministry for the candidate, but how will the candidate affect the congregation's ministries?

Careful attention to charism and the congregation's own tradition is essential. In my religious order, the Society of Jesus, our charism emphasizes active work in the world. Our constitutions are very clear. Candidates are only to be accepted if they are capable of engaging in active, apostolic work. Thankfully for the church, there are many charisms alongside that of the Society of Jesus that allow a multiplicity of gifts for the church and the people of God. Vocation directors and their colleagues should look carefully at the spiritual resources of the community, the plan of the founder and the expression of that plan. It could well be that an outstanding candidate for one religious order would not be considered by another. Be cautious in making too many allowances for a candidate's physical condition if your charism emphasizes activity, independence and vigorous apostolic commitment. It seems unlikely God would call a person who is dis-

abled by chronic health concerns to a group God has called to an active life in the world.

Chronic illness always has implications for ministry. Those implications can be for the person with the illness and for those in the community who need to care for that person. For example it may be that a candidate has an excellent contemplative potential, but caring for that person might limit the work of contemplation for the community. Vocation directors need to be cautious in accepting a person with a chronic progressive illness because of the impact this could have on other community members. It may well be that a candidate has a number of outstanding features, but other issues would divert the community from its principal obligations. Taking a chance on a candidate and risking damage to the work done by a congregation does not make sense.

Resources matter

Resources are another important consideration. This area is not just practical but has to do with the current reality of your congregation, the "signs of the times." Simply stated, if a congregation is dwindling, aging, and increasingly strapped for resources, then vocation directors need to be careful about accepting a new burden for the community. Likewise if a person requires expensive medications and therapies, then one needs to see if this expense is going to make life hard for older, frail members of the community to whom the community, in justice, already has a commitment. Thinking about the future is also part of the vocation director's resource assessment. This means not only considering the prognosis of the candidate, but the prognosis for the community's ability to care for and assist members who need help. Currently many large institutional communities provide significant help in the instrumental activities of daily living. In these communities meals are prepared, food is served, there is no need to shop for groceries, bills are paid by individuals in the treasurer's or superior's office, and individual religious are supported completely by the community structures. Communities like these frequently have members with chronic health issues. It's easy to imagine a new member with talents and some health issues fitting into the rhythm of such a community. The problem for active religious orders is that communities like these are not likely to be around for long because of dwindling vocations. Large monastic communities set up like this will likely persist in a few settings, but declining vocations could also make accepting a new individual with health problems an unfair

burden on the community. Vocation directors need to think about who will be around to help in the future and the type of community where people will live in the future.

Some of the issues regarding resources need to be tried out for a community to understand the reality of what it would mean to accept a member with a chronic health issue. This would especially be the case with a person with a chronic disability. Trial periods in the community are valuable for any type of candidate. But in the case of candidates with a chronic illness, they can be even more crucial. The candidate can see if there are accommodations a community is willing to make to provide for his or her independence. The community can see if the candidate is serious about the ministry and fits in well, or if he or she is overly focused on personal issues, no matter how understandable that focus may be. Likewise, both candidate and community may come to understand that a truly wonderful individual may not be called to a particular community because of a lack of resources to provide needed assistance for the candidate and the potential for limiting the ministerial freedom of members of the community. It may also be the case that trial living periods lead to good challenges on both sides. Community members can learn to move a bit out of their accustomed routines and recognize that God is calling them to make some accommodations for a wonderful new member. And the candidate can realize that he or she faces a process of give and take in discerning God's call and in integrating into the community.

Vocation ministers are called upon to exercise prudent judgment for every serious candidate. When a candidate has chronic health concerns, the vocation minister must gather even more information and consider a host of additional issues. I have suggested that vocation directors who are working with an individual with a chronic health problem need to consider three main issues: the impact of illness on the person, appropriate evaluation by health professionals, and the resources of the community (with resources being understood very broadly) to assist the person both now and in the future.

Perhaps some readers are disappointed that I have not provided a list of diagnoses that qualify or disqualify for religious life. However I see a variety of diagnoses among the religious I know well. I recognize that there are religious without any chronic health problems who are highly problematic for the community, as well as some with a tremendous burden of illness who contrib-

ute much apostolically and edify the community. That complex picture makes me advocate for a careful, honest, and realistic assessment on a case-by-case basis. +

Case study: setting a health policy for a missionary order

The challenge of meeting health care needs of members of religious congregations can be formidable. For a congregation, such as my own, whose charism is transcultural missionary work, the challenge is that much greater.

Our active members must seek medical care from reliable providers in the countries where they are living and working or in a neighboring country. Some countries do allow expatriates to participate in the nation's health care program. Others make the premium for foreigners so high, it isn't cost effective to participate. Still other times, a missionary engaged in a ministry of "service" is able to obtain a discount for medical care.

We do find that the cost of exams and treatment is, almost without exception, much less than what we would pay here in the U.S. However, often there is a problem in finding quality care, especially in underdeveloped countries where many of our members minister to the poor and marginalized.

All this points to the need for congregations whose primary focus is overseas transcultural work to be especially concerned about the health status of those applying for membership. It may well be appropriate for religious communities whose members live and work in the U.S. to accept applicants with problems such as diabetes, chronic cardiac disease, deafness or blindness. But if it is expected that the members will live and minister in areas where even primary medical care is essentially lacking, it would be a disservice to the individual and the group to encourage people with these problems to seek admission. Thus the Maryknoll Sisters expect applicants to meet a high standard of good health for admission.

—by Dolores Congdon, MM, of the Maryknoll Sisters of St. Dominic, who is administrator of outpatient care at the Maryknoll Sisters Center, Maryknoll, NY

Catholic tradition offers a “three font principle” for evaluating moral issues, including those raised by candidates with chronic health concerns. One must examine the intention, the act itself and the circumstances.

Ethical issues raised by candidates with health concerns

by Thomas A. Nairn, OFM and Dawn M. Nothwehr, OSF

In the last 20 years both the church and U.S. society at large have begun thinking of people with disabilities as people with rights and with skills and talents to share. When Congress passed the Americans with Disabilities Act in 1990,¹ Americans were reminded of the many issues of justice and equal access associated with people with disabilities. Well before that legislation, the U.S. Catholic bishops addressed similar concerns in their 1978 and 1989 release of, “Pastoral Statement of the U.S. Catholic Bishops on People with Disabilities.”² A main message in both versions of the bishops’ document was that *all* Christians are called to minister in some way. This theme was further developed in 1995, with the bishops suggesting that a disability does not in itself disqualify a person from the priesthood and that dioceses should consider such cases on an individual basis. They then suggested that dioceses and religious communities should provide appropriate counseling to help persons with disabilities discern their vocations. Another statement of the bishops, issued in 1999, notes: “We welcome qualified persons with disabilities to ordination, to consecrated life, and to fulltime, professional service in the church.”

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Moral dilemma, discernment or both?

Such statements certainly set the stage for a prophetic witness of the church in the third millennium. Nevertheless they also cause difficulties for a vocation director serving the concrete needs of her or his community. Since in many religious communities the average age of members is in the 70s, is it reasonable to consider receiving new members with a chronic illness or disability? What are the elements of a consistent, fair policy in regard to the health of applicants? How much special treatment related to the applicant’s health condition is acceptable in terms of the rights and responsibilities to the community as a whole or in a ministerial setting? How does a community deal with diseases that render a person increasingly disabled? How does one balance the community’s or ministry organization’s responsibilities to its members, actual and potential, and the individual member’s responsibilities to the community?

Certainly it is not possible in this article to resolve all of these questions. Nevertheless, we will try to provide an ethical framework for weighing some of the central issues when a community discerns membership for a person with a chronic illness or disability. The Catholic moral tradition has suggested a “three font principle” as a useful way to analyze any moral action. This principle understands 1) the *intention* as the internal dimension of the moral action in which one determines the purpose of the moral action; 2) the *act-in-itself* as the external, observable material element of the moral action; and 3) the *circumstances* as the set of the conditions that form the context in which the moral action takes place and that qualify that action in some way. Although one may begin with any of these elements, we begin with circumstances.

Circumstances: involvement of the applicant and the community

The applicant

What special *circumstances* are present in vocation discernment with a person with chronic health concerns? As with any vocation discernment, two parties are involved, the applicant seeking membership and the vocation director representing the community. Each validly comes to the discernment with different concerns and questions. It is also critical to realize here that each party comes with unequal power. The vulnerability of the applicant in relation to the person who is able to say “yes” or “no” to her or his future life choice is tremendous. Since the community is asking the applicant for a great amount of self-disclosure, vulnerability increases proportionately. Additionally, when that person has a disability or chronic illness, the obvious issue of the fittingness and fitness of the person to be a member of the community creates a situation where the person cannot help but feel exposed. Because of this vulnerability, it is important to not allow a single dimension of a person’s identity to define her or him in relation to the community. To ensure that this occurs, a community needs to develop a common standard for discovering the fittingness of *any* applicant who seeks admission into the community. The person with chronic illness or disability is then considered according to the standards in effect for all applicants.

The community

It is also a fact that the community is vulnerable during the discernment, but this is less obvious. In ways that are subtle—or not so subtle—every new member changes the community for better or for worse. The community can deal with its own vulnerability through its understanding of its charism, that is, in terms of its identity and mission. Regarding the question of identity, religious congregations and their individual members need to ask: “What sort of persons ought members of this community to be because of their fidelity to the community’s *charism*?” Similarly, the question of mission in the foundational moral sense asks, “What sort of actions ought I to perform because I believe in Jesus Christ?” Placed in the context of the religious community, the question becomes: “Gifted with a particular charism, how ought the members of this congregation to engage in the mission of the church?” Each of these questions brings with it elements that can validly challenge the fittingness of certain candidates to become members of the community. Nevertheless it is important at this level to realize that the

determinative question is not the issue of the disability but whether the applicant—for whatever reason—has the ability to enter into the charism of the community.

Sources of moral wisdom

Sources for finding direction to respond to these questions will no doubt include the rule and constitutions of the community, along with its other foundational documents, patrimony and heritage. Presumably, those documents hold the narrative around which present community members have cast their lot, and the wisdom and passion that burns in the heart and soul of all the members. As such, these are significant sources of moral wisdom for the community—especially in the affective sense.³ Through what is expressed in those documents, the deepest place of unity of the community can be found. On the one hand, the charism is the place of unity for the community. On the other hand, it also may call the community to something new, or prophetic, or that expands the demands on members to adjust to the needs of an “other” who is not “the usual.”

Intent: charism, identity, mission, ministry and the practical

The question of intent seems rather straightforward: *Why* would a particular community either accept or reject a particular applicant with a disability? As discussed above, elements of identity, charism, mission, and ministry make it possible to identify the communal context that frames the boundaries for whom the community can accept and whom it must reject as not “fitting” with its purpose. In practice, however, the question of intent may not be this straightforward. The real reason for rejection may simply be that the members of the community are afraid. People respond to what is new, different and not normal in a wide variety of ways, depending on their own past experiences and presuppositions. In communities where the population is older or few in numbers, issues of personal diminishment can easily color how vulnerable present members feel in response to the possibility of welcoming a chronically ill new member. Or the threat might be a fear of inadequacy: “What if I’m with her, and she has ‘an attack?’”

If a community is to accept new members with health concerns, it must deal with these fears in a spirit of openness, affection, and affirmation for members who express such fears. Current members need to be free to express their true understanding (or lack of understanding), their fears and their hopes. Repressed fears

and hopes can fester and draw energy from the community.

Education and formation processes are one approach for uncovering the level of knowledge and receptivity in the community for receiving new members with chronic illness or disability. It is important that the entire community be involved in these processes, because the entire community will be affected by the presence of the new member in one way or another. Once there is a common knowledge base, it can be easier to determine the perception within the community of what ought to be “the norm.” Once the unspoken norms of a community are verbalized, it is possible to discern the actual common purpose of the community. Then the question of how the applicant with her or his disability “fits” this purpose also becomes clearer.

The act: openness, transparency, full disclosure

Not all communities should contemplate receiving chronically ill persons as members. Questions of justice and respect are as important as questions of care and concern from both the side of the community and the side of the applicant. The applicant needs to be open and forthcoming concerning the prognosis regarding her or his illness or disability. The community

How to handle medical information once you have it

This article and others in this edition encourage vocation ministers to obtain in-depth medical information from candidates with chronic health concerns. That raises the question of how medical information is stored and who has access to it. How does a vocation minister safeguard the privacy of the applicant while ensuring that community decision-makers adequately understand the diagnosis and its implications?

The Religious Formation Conference will address such questions in the “Record keeping” section of its forthcoming *Resource Manual, Volume 3*, slated to be published in the summer of 2006. For more information, contact Religious Formation Conference, (301) 585-7649, RFC@relforcon.org or www.relforcon.org.

needs to ensure respect and confidentiality concerning what is disclosed and provide for proper legal permissions and safeguards. The possibility of a “no” must always be kept at the forefront in the discernment, so that there will be no surprises for either the community or the applicant.

In order to consider a chronically ill candidate, a community needs to assess its own capacity to provide adequately for the person’s needs. Considerations should cover the social, political, economic, as well as the spiritual resources of the community. Will the new member who is chronically ill likely be looked upon as too different from other members of the community? Will he or she be seen merely as an object of care by the community and not as a full member? Is the financial state of the community such that it can afford the necessary physical changes in building structures or expensive medications? The answers to these questions may in all truth be a “no.” This should not necessarily be seen as a problem. In these circumstances, however, the task of the vocation director is not finished. The community still has the responsibility of informing the candidate in a sensitive way of the *reasons* for its rejecting and the *process* of how and *on what basis* the decision was reached.

Five-step framework for moral deciding

Understanding the three fonts of morality—circumstances, intention, and the act itself—can form the basis for a five-step framework for vocational discernment with a person with illness or disabilities. This “three font principle” enables us to uncover the moral issues in broad descriptive terms. Systematically working through a particular case using this five-step framework helps us utilize that information to raise the morally significant factors with greater specificity. Using an inductive reasoning process, we are able to not only probe the various dimensions of the question for moral value, but we can also place the various factors in conversation with one another in order to attain greater clarity. The focus in this instance is actually deciding on a specific action in an actual case. In what follows here, it is presumed that the question of the applicant’s general capacity for religious life is not in question.

1. Acquire appropriate information

It is important to ask from the very beginning what are the *ethically significant* questions in any case where a person with a chronic illness is requesting membership in a religious community. The community has a

right to know the severity of *debilitation* that accompanies the chronic condition. How does this debilitation affect the capacity for the applicant to enter into the charism of the community and its mission?

A related question deals with applicants' perceptions of their condition, their self-care habits and their consistency in caring for their health needs.⁴ A person who is a diabetic and is meticulous about her diet—testing blood sugar levels, getting rest and exercise—would likely present less concern to a community than one who regularly cheats on her diet and neglects regular exercise and rest. Similarly, a person who requires much personal care but who exudes a spirit fully attuned to the religious community may be in quite a different circumstance from one who has a lesser disability but has not come to terms with it.

A person who requires much personal care but who exudes a spirit fully attuned to the religious community may be in quite a different circumstance from one who has a lesser disability but has not come to terms with it.

Another dimension of information gathering is to prioritize the ethical values and other motivations involved. Such values and motivations need to be considered both from the point of view of the community and that of the applicant: How does the presence of this particular chronically ill person affect the life and spirit of the community? Is the only reason for rejecting an applicant a comfort with things as they are? Is the applicant accepted because of a true “fit” with the community or because he or she is being used to push a particular “prophetic” agenda? Why does the applicant seek membership in this particular community? What can the applicant identify as her or his motive for living life with her or his chronic illness in this religious community? What values, principles, or *prima facie* obligations undergird the choice to accept or reject the applicant?

2. Dialogue with and seek advice from others

The nature of the medical condition may demand that the community seek the advice of qualified profession-

als. Is the community certain of the responsibilities that it is taking on by accepting an applicant with a particular condition? Besides the typical information that a vocation director seeks—the spiritual maturity of the applicants, their psychological capacities, their emotional coping capabilities—the community may need data about possibilities for self-care, costs of health maintenance, reasonable potential to qualify for medical insurance, resources available to the person from outside the community, probable progression of the debilitation in the foreseeable future, and the ability of the applicant to undertake her or his responsibilities toward the community. Legal issues also need to be respected. Any conversations with such professionals, for example, need to be in accord with standards of informed consent and confidentiality. One needs the expressed written permission of the applicant for many of these conversations. As government provisions regarding privacy continue to expand, this will become even more important. Finally, although legal matters surrounding the provisions of the Americans with Disabilities Act are usually not at issue in vocational discernment, there may be rare situations where it is reasonable to seek legal counsel in trying to ascertain what is fair both to the applicant and to the community.

3. Making a reasoned and reflective judgment

Acquiring information and seeking the opinions of others must finally lead to a judgment regarding the suitability of this particular applicant with this particular disability entering this particular congregation. Clearly both the good of the community and that of the applicant are at stake, and absolute certitude regarding either of these goods is beyond any human capacity. It is here that the criteria of justice and fairness and the possible ways of sharing the burdens and benefits need to be laid out as clearly as possible. One possible way to begin is to list the reasons for deciding in favor of accepting the applicant and then listing those against accepting the applicant. Next to each reason one should also list the values that are being upheld by that reason. When this process is complete, it is important for everyone involved in the decision to step back and prayerfully reflect upon both the reasons and the values implied in those reasons. In this way, one is not only listening to logic and reason but also the affective ways of knowing, such as intuition, wisdom of the heart, and past experience. If any of the decision makers feels uncomfortable with the direction of the decision, it would be important to review again this process of making judgments.

4. Deciding

In the last analysis the correct decision will be based on a reasoned consideration of the burdens and benefits to the community and on justice and fairness to the applicant. As already discussed, such decisions are not simply the product of logic, and often the best indicator that the community has made the right decision will be a sense of peace with the decision. This does not mean that the decision is without emotional pain. Rather, the spirit of peace comes from those involved being able to say with integrity that they have been faithful to their charism, to the applicant, and to the Gospel.

5. Implementation

Decisions often entail the making of other decisions. If the community decides to accept the applicant, the decision makers will need to prepare the members of the community to accept and be a companion to their new member. If the decision is to reject the applicant, the community must decide what and how it will communicate with the applicant. Initially, the pain of the decision may present an obstacle to direct communication. Nevertheless, the community must make known its concern for the applicant, even in its rejection. The reassurance of care and concern can blunt the pain of personal rejection and help the applicant to refocus his or her life in a positive manner.

The church's moral tradition is a tool that can be of help in a great variety of decisions. Concentrating on the three founts of morality—the action itself, the intentions of the agent, and the circumstances in which the decision is made—can provide guidelines for religious communities as they enter into discernment with applicants. These considerations can be of special help as communities try to separate appropriate reasons from inappropriate ones as they reflect upon whether to accept someone with chronic disease or disability. ✚

1. "Facts About the Americans With Disabilities Act," <http://www.eeoc.gov/facts/fs-ada.html>, accessed 9/21/05.

2. This document was a revision of their 1978 statement, "Pastoral Statement of U.S. Catholic Bishops on Handicapped People." The revised language and changed title reflected the growth in awareness and sensitivity on the part of Catholics, including the bishops. For our purposes, the term "disability" will follow the definition of the Americans with Disabilities Act, which is: "physical or mental impairment that substan-

tially limits one or more major life activities; has a record of such an impairment; or is regarded as having such an impairment." "Chronic illness" means any illness or medical condition that lasts over a long period of time and that sometimes causes long-term changes in the body. See *Encarta English Dictionary* (North America) s.v. chronic illness.

3. See Margaret A. Farley, *Compassionate Respect: A Feminist Approach to Medical Ethics and Other Questions*, 2002 Madeleva Lecture in Spirituality (New York: Paulist Press, 2002) pp. 44-82. Also, Kathryn Tanner, "The Ethics of Care That Does Justice," *Journal of Religious Ethics*, 24 (Spring 1996) pp. 171-191. See also Martha C. Nussbaum, *Upheavals of Thought: The Intelligence of Emotions* (New York: Cambridge University Press, 2001).

4. Edward Zaorski, "Religious Vocations and the Dis-

In the last analysis, the correct decision will be based on a reasoned consideration of the burdens and benefits to the community and on justice and fairness to the applicant.

abled Person," (unpublished document made available through the Religious Formation Conference, 8820 Cameron Street, Silver Spring, MD 20910-4152) suggests the following ten questions as useful in this process. 1) What triggered your interest in religious life? 2) Describe a normal day in your life—your abilities and your disabilities. 3) Do you need any assistance in daily activities? What kind of assistance? How do you get it? What is your attitude toward your own needs as you perceive them? How much initiative do you take on your own in order to meet those needs? 4) What talents, expertise or knowledge do you feel you can offer this community? 5) If you could improve yourself, what would you focus on and why? 6) If you were ever discriminated against, how did you react toward your discrimination? 7) Can you see your impairment limiting your priestly or religious duties, and how much can be adapted to alleviate these limitations? 8) What is your understanding of celibacy? 9) How do you perceive sexuality with your impairment? 10) What has been your previous history or past experiences with the church? ✚

Here is one woman's story about how chronic health problems affected her person, her ministry and her life in the community.

Living religious life with chronic illness

by Mary Therese Johnson, OP

The year 2000, the Jubilee Year, a time to “open wide the doors,” marked a significant change for me both personally and professionally. It felt like doors were closing to me rather than opening. In July of that year I was diagnosed with Crohn’s disease just before starting a new ministry as a co-director at our Collaborative Dominican Novitiate. (Crohn’s disease is a chronic disorder that causes inflammation of the digestive tract.) Of course I was determined not to let this condition get the best of me. With hope that my health issue would not be a problem since I had caught it early, I set off for St. Louis, MO.

Soon strange things began to happen. Severe pain raced through my body each day—first it attacked my neck, then it jumped to my feet, then it ran through my shoulders to my hands, and in the evening the pain rested in my back and knees. There I was, in a new ministry, in a new place, with a new health condition. Where would I go for help and support? How could I be fully present with my community of novices and my co-minister?

Each day held its challenges, and I gave my all to try to make everything work. And the roller coaster ride began. After a long search for doctors, I found some help and went for physical therapy, discovering that warm-water swimming helped immensely. I would be

up on top of the roller coaster ride, feeling that I was getting better, and then I would come rushing down with a setback. When the roller coaster ride wasn’t stopping, I also sought help through counseling.

Again I set my hopes high that the health issues would be manageable so that I could be fully engaged in community life and ministry, as I so strongly desired. However, much of my life was consumed with self-care and pain management, so it became increasingly difficult to be faithful to my commitment at the novitiate. Ultimately, with much prayer and consultation, I made the decision to resign.

Fortunately my congregation supported and encouraged me to be attentive to my healing. I had a three-month sabbatical, sought new medical help, and was further diagnosed with fibromyalgia (a chronic musculo-skeletal pain and fatigue disorder) and chronic fatigue syndrome. Now, after coping with these health concerns for five years, I am able to engage in community life and ministry with new wisdom. The conditions I have are chronic. They are still with me, and I have learned to accept this reality. The choices I make affect my whole person, and so I make those decisions wisely.

I share this background because there may be a correlation with people who are entering religious life. Beginning a new way of life is challenging for anyone, even if he or she is healthy and enthusiastic about the venture. Add to the mix a chronic health condition that has serious implications, and there is a possible meltdown waiting to happen.

In this article I will address the emotional and spiri-

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tual impact of my chronic illnesses, as well as the impact on community life and on ministry. Then I will share some suggestions for vocation ministers who are working with inquirers who have chronic illnesses.

The emotional and spiritual impact

I believe that the human body, mind and spirit are intimately connected. So when the body is suffering, all parts suffer. When a significant relocation adds further stress, the emotions are perhaps overactive and contribute to stress on the body. Exhaustion compounds the situation and affects thinking, physical activity, as well as sleeping and eating patterns.

In resigning from my ministry I struggled with a sense of failure, of letting others down, of being “a wimp.” I was scared about the future.

As a woman religious my spiritual life is vital to my being. Fortunately I found a compassionate spiritual companion in St. Louis who listened well and helped me to process what was happening. Many tears were shed. Through this initial stage of coping, my prayer became the glue that held me together. I engaged in more intense dialogue with God. Music, journaling and spiritual reading helped me express what was going on inside. Yet at times even my prayer life seemed to be a desert experience.

Though my closest friends were far from St. Louis, I knew understanding and support from them. I didn't want my family to worry, so initially I kept my pain from them. I sought other emotional support and guidance from my provincial and a therapist. Luckily I am resourceful and have developed coping skills over the years. Yet, even with all the love, support and understanding, my spirit was devastated.

My head and my heart eventually led me to a significant decision to resign from my position as the co-director at our novitiate. I could no longer resist the messages my body was communicating. While coming to that decision I struggled with the sense of failure, of letting others down, of being “a wimp.” I was scared about the future.

The future came quickly. I had no idea what lay ahead of me. I participated in a three-month wellness sabbatical. With loving support and the space to heal, my spirit began to mend. Yet my body continued to experience extreme pain and exhaustion. Now what? It was clear to me that I could not return to my former way of being. A struggle between my body and spirit continued. Finally I could struggle no longer. Through the struggle I did learn to take a day at a time and to be my own best friend. I came to realize that I was not a “super sister” and that I could say no and still be a good sister. I needed to put limits on what I could do. Doctors, therapists, spiritual director, friends, community and family all contributed to my well-being. It is very humbling to rely on others. In the past I tried to avoid being vulnerable; now I realize that it has the potential for tremendous wisdom and growth.

Participating in a study on chronic fatigue syndrome at DePaul University gave me important knowledge and skills to manage my disability. I began to befriend my body with all its pain and shortcomings. In doing so I became less resistant to the “dis-ease.” I found help through alternative medicine, especially through acupuncture, massage therapy and warm-water exercise. The expense of these aids added stress because I felt guilty that I was a financial burden.

The emotional and spiritual impact of chronic illness is very tangible. I am constantly aware of my need to pace myself and to engage in healthy self-talk. I do not want to define myself by or be a victim of the chronic conditions.

Impact on community life

I have lived in community my whole life. Community life affects the well-being of its members, and each member influences the well-being of the community. When my life was changing because of illness, I was in a novitiate community. I saw myself first as “sister,” one of the community, who was also a director. I had a good relationship with the novices. My role as director, however, was always present in the eyes of the novices. Living in the novitiate community with an illness complicated the situation. The intent of their year is to discern their vocations through prayer, study, ministry and community. When one of the directors has a serious health concern, the focus can be skewed, even if unintentionally.

The novices were aware of my situation and wanted to be sensitive to me. I needed assistance with some of my household tasks. I also needed a companion for some of my tests, as I was unable to drive myself. As part of the novitiate year a professional facilitator helped us process our life together. Naturally concern for my health was a significant issue. It was difficult for me to be the focus. I sometimes translated it to, "I am a problem." My identity as a person was changing, and I didn't know how to be "in community." I did try to be present in community, yet emotionally I was feeling disconnected. I became more cautious. The stress of the situation added to the pain of my illness.

I shared with the community my decision to resign. I had planned to leave in June, at the end of novitiate year. However the community encouraged me to leave sooner. Leave-taking is a difficult process for me. The pressure of packing, completing my records and saying good-bye affected me emotionally and physically. When I left the novitiate, I lived in community on sab-

Community members graciously welcomed me back and accepted my limitations. They took on more responsibilities for household tasks, helped me with my laundry, and in the beginning, drove me to my many doctor appointments. We intentionally talked about the belief that, "We are all doing the best we can."

batical. There I experienced relief of pressure. We were all engaged in healing. Being able to be and speak freely enhanced the healing for me. I learned so much from what the others had experienced. I also felt respected and understood.

After the sabbatical, I returned to the community I had been with before the novitiate. Now I was living with my peers, so I was not returning to the pressure of being the director and role model as I had been in the novitiate community. Clearly I was unable to do certain things. The community members graciously welcomed me back and accepted my limitations. They took on more responsibilities for household tasks, helped me

with my laundry, and in the beginning, drove me to my many doctor appointments. We intentionally talked about the belief that, "We are all doing the best we can." Though the community never pressured me, I felt that I was not doing my share and I would apologize, though I need not have. I was frustrated sometimes when others would do things for me that I could do for myself. I tried to show my appreciation despite my frustration. I believe that the love, understanding and concern of my local community, as well as my religious congregation, have been central to my healing as I live with chronic illness.

Impact on ministry

My 35-plus years in religious life have been filled with meaningful service. I am the person I am today because of the many relationships and experiences in ministry. Chronic illness changed my way of being in ministry. For the most part, ministry has nourished my spirit. I've been an educator, director of religious education, pastoral minister, liturgist, campus minister, vocation director, spiritual director and co-director of the novitiate. I served on different committees. I have often said yes to requests for assistance with projects. Perhaps this over-commitment contributed to the onset of my conditions. When full-time ministry was impossible for me, I really had to examine my perception of self-worth that depended on what I did. I want to be a contributing member of the congregation.

I have already mentioned some of the other emotional pressures involved in this life-changing experience of chronic illness. One difficult part of the ordeal was applying for Social Security Disability. I filled out numerous forms, collected documentation, spoke with lawyers and was turned down twice. I was discouraged and felt useless. Yet on the third appeal I was accepted for assistance. I report to the Social Security Administration, but there is no guarantee that the financial assistance will continue.

Today my ministry is rewarding. I am able to draw on the skills and experiences from my past. My ministries include part-time service at the National Coalition for Church Vocations and at the Hesburgh Sabbatical Program; plus I free-lance as a spiritual director and retreat facilitator.

Sound full? This load is very manageable because it gives me the flexibility I need to take care of myself, and the ministries give me energy. My biggest challenge, now that I am not in a flare-up mode, is to re-

member to pace myself. If I overextend myself, there are serious consequences. I take one day at a time. I continue to devote time to exercise, massage and acupuncture. I try not to take things and people for granted. Most importantly I have learned to live a more balanced life that is both active and contemplative.

Suggestions for vocation ministers

Storytelling can often give us helpful insights. Hopefully my story has given you greater sensitivity to

It *is* possible for people to live a healthy religious life with chronic illness. However, I would caution you to find evidence that the seeker is able to cope successfully with the stress of having a chronic condition.

some of the effects of living religious life with chronic conditions. Perhaps you can see some correlation with women and men who are inquiring about membership in our congregations. It *is* possible for people to live a healthy religious life with chronic illness. However, I would caution you to find evidence that the seeker is able to cope successfully with the stress of having a chronic condition. Invite the person to participate in a mission experience (at least one or two weeks long) where he or she gets a taste of the lifestyle beforehand. Go on the Internet and find information about the condition. Talk to health professionals for their wisdom. Have conversations with religious who are living with chronic illness. If candidates are new to the experience of chronic illness, it would be prudent to suggest that they deal with their health first. Those who have learned good coping skills can enter more fully into the initial membership process. They often have great wisdom to share with others in community. +

Canon law gives the leaders of religious communities a fair amount of discretion when it comes to questions of health in applicants.

What canon law says about health concerns in prospective members

by Eileen C. Jaramillo

When John Paul II promulgated the revised *Code of Canon Law* in 1983, he spoke very clearly about the purpose of law. He said that the law “is in no way intended as a substitute for faith, grace, charism, and especially charity in the life of the Church and of the faithful.”¹ Rather it is an instrument which lays down certain norms to facilitate order in both individual and ecclesial life, so that the work of the Spirit might be fostered.

In order to address what the Code says about health issues, it is important to begin by considering the context. The Code is divided into six books. Part three of Book II, “The People of God,” is the setting for institutes of consecrated life and societies of apostolic life. Its laws are based on the assumption that the Spirit has been active in the founding of a particular institute or society. It also provides the necessary context so that a charism can continue to operate freely in cooperation with the Spirit for the sake of a particular mission. One way the Code accomplishes this task is by allowing religious institutes or societies to address various matters in their own constitutions, secondary handbooks, and directories. Also included in this section are the canons on individuals who live an eremitical life or a life of consecrated virginity. Additionally openness to the gift of the Spirit is seen in the law in this part of the Code because it envisions new forms of consecrated life. Passing through various stages during their

discernment process, these new possibilities are governed by the canons on Associations of the Faithful which can be found in Book I. This particular book contains the foundational canons for the rest of the Code.

A rather significant canon for both religious institutes and societies of apostolic life² mentions several critical areas for the competent superior³ to address when admitting those who might desire to one day be incorporated in a particular institute or society. With no parallel in the prior Code, it introduces new issues that had never before been considered. Canon 642 says, “With vigilant care, superiors are only to admit those who, besides the required age, have the health, suitable character, and sufficient qualities of maturity to embrace the proper life of the institute. This health, character, and maturity are to be verified even by using experts, if necessary, without prejudice to the prescript of canon 220.”⁴

While the law is very specific about the applicant’s standing in the church⁵ and the required age⁶ as stated in various canons, canon 642 prefers to use the term “vigilant care” regarding other matters. Vigilant is defined in dictionaries as alert and watchful in order to avoid any danger. Care is defined as meaning a heavy sense of responsibility. Vigilant care, then, must be the norm that the superior operates under when deliberating about health, character and maturity. The person being considered must be capable of living a commitment which entails a genuine gift of self in response to the Gospel. The individual must have the capacity to live a communal life of service to the poor. (Poor is being used in the broadest sense of the word since every institute or society was originally founded to address a need.) This is true even when the community is cloistered. Since the superior knows the specific charism of the institute or society, the canon is brief so as to allow a certain amount of discretion about health,

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character and maturity as they relate to the particular institute or society. The vocation minister can be helpful to the superior in this particular area by making a preliminary assessment of an individual during the initial dialogue session.

The term health, as used in the canon, refers to the physical, mental, and emotional health of an individual. According to the canon, these aspects of the individual can be verified by using experts, if necessary. There is no definitive list of what information should be requested in each of these areas. When deciding what to require, the criteria should always be that which is essential in order to assist the superior in ascertaining the suitability of a particular applicant for admission. If health, character and maturity can be adequately determined without experts, then the law does not require that they be used. Each situation needs to be assessed individually to make the determination.

In terms of health, the basic thrust of this article, it is usually prudent for communities to require physical, dental and ocular checkups. Some communities are testing for HIV antibody as a part of the battery of medical tests. (See “Developing admissions policies in regard to HIV,” by Jon Fuller, SJ, M.D., on page 18.) Reputable doctors can be chosen by either the applicant or the institute or society. Psychological testing and interviewing are also advisable.⁷ In cases in which it may become necessary to gain more insight into a particular condition, additional information, such as a second opinion, should be requested. Difficulties can be avoided later on if there is clarity in the early stages of the discernment process about a particular health issue and its ramifications for living consecrated life. A vocation minister should tell the applicant what information will be requested and that appropriate release forms, which conform to both canon and civil law, will need to be signed.

Protecting the candidate’s reputation

Canon 642 also speaks about due regard for the prescriptions of canon 220. This particular canon says, “No one is permitted to harm illegitimately the good reputation which a person possesses nor to injure the right of any person to protect his or her own privacy.”⁸ A person’s reputation might be harmed by revealing a secret. While the highest form of secrecy in the Code is the seal of confession, there are many other forms of secrecy which are mentioned. One of them pertains to the role of a council in a community.⁹ A person’s reputation could also be harmed through slander or

defamation. Whether it is a vocation minister, an admission board, a superior, a council or someone else who might be involved in the various stages of incorporation, the norms of moral theology should be followed regarding a person’s right to a good reputation when it comes to revealing any information about health, character or maturity.

The canon also speaks about protecting one’s privacy. In regard to health issues, one of the areas of concern is past medical history. There may have been a pregnancy, a sexually transmitted disease, or something else. Past experiences or illnesses may or may not

“Vigilant care,” must be the norm that the superior operates under when deliberating about the health, character and maturity of a candidate.

have an effect on the person’s overall health and ability to live religious life. Who really needs to know this information, as well as how much they need to know, needs to be addressed. Another issue is who can review the results of psychological testing. A community should have a policy in place about who is authorized to have access to the various health issues. The vocation minister should make the applicant aware of who will see what.

Religious orders with priests

If the institute or society is clerical, it is important to know that canon law stipulates certain irregularities to ordination as stated in canon 1041. The major superior must state in his dimissorial letters¹⁰ that the candidate has not contracted any of these. Some of these irregularities relate to health issues. Only a general understanding of these issues will be given since each one is complex. In accordance with canon 1041, 1^o an individual who suffers from some form of amentia or other psychic illness is not to be ordained when it is judged that he is incapable of fulfilling the duties which flow from ordination. When stating this irregularity, the canon clearly indicates that experts have been consulted in making such a determination. The investigation into this health matter must be very thorough. Temporary psychic illnesses do not fall into this category. Canon 1041, 4^o indicates that a person who

has voluntarily committed a homicide or participated in a completed abortion is also irregular for ordination. While the applicability of this aspect of the canon must be carefully considered in each situation in order to determine whether an irregularity has been incurred, it is also important to note that the emotional health of the individual regarding such traumatic situations should also be assessed. According to canon 1041, 5° a person who has gravely mutilated himself or another or who has attempted suicide is irregular for ordination. These issues also have to be looked into very carefully because they can give rise to some very difficult questions, such as a vasectomy and whether an attempted suicide is genuine. Whether it is any one of these health concerns or the other irregularities mentioned in canon 1041, a canonist should be consulted. When appropriate, a dispensation should be obtained.

For all types of communities, it helps if vocation ministers are prepared to make referrals. In accordance with the canon, what might not be possible in one community might be very acceptable in another. When this is the case, then it is the task of the vocation minister to refer the person elsewhere. Vocation ministers can network with other communities, diocesan offices and organizations in order to know which communities are open to people with various disabilities. At the same time, however, there may be individuals who are not suited for living any kind of community life. When this is evident, the vocation minister should alert inquirers to other kinds of church vocations.

In conclusion it is worth noting what is so beautifully expressed in canon 662: "Religious are to have as the supreme rule of life the following of Christ proposed in the Gospel and expressed in the constitutions of their own institute."¹¹ A prospective member should see the vocation minister exemplify this canon. For vocation ministers one aspect of expressing the Gospel in their community's constitution is to understand how various health issues can affect an individual's capacity for embracing community and mission. This takes on added dimensions if the institute or society is clerical. Canon 642 does not go into great detail about health matters, but is satisfied with stating general principles and leaving the application to those responsible for admitting new members. This is one more sign of the Code's trust in the elected leadership of religious communities. ✚

1. John Paul II, "Apostolic Constitution *Sacrae disciplinae leges*," *Code of Canon Law*, Latin-English Edi-

tion, New English Translation, (Washington, DC: Canon Law Society of America, 1999) p. xxix.

2. The Code contains specific canons for societies of apostolic life. One of these canons, canon 735, §2, refers these societies to canon 642.

3. Canon 641 indicates that the right to admit candidates to the novitiate belongs to the major superior according to norms of the proper law. Such norms indicate whether a deliberative or consultative vote of the council is necessary prior to admission. Unlike the 1917 *Code of Canon Law*, the 1983 Code is silent about a period of postulancy/candidacy. However various documents from the Holy See speak about some type of probationary period.

4. *Code of Canon Law*, p. 209.

5. Canon 597 says that a Catholic who is endowed with the right intention, has the qualities required by the *Code of Canon Law* and the proper law of the institute, and does not have an impediment can be admitted. Canon 645 speaks about the documentation which needs to be gathered.

6. Canon 643 lists five requirements for the novitiate to be valid. One of these is the age of the individual.

7. See Donna Markham, OP, "Issues of Sexual Diversity and the Call to Religious Life," in *HORIZON*, Vol. 28, No. 2, Winter 2003 (Chicago: National Religious Vocation Conference) pp. 8-12. In a section of her article this psychologist indicates that we must screen out people who are driven by self-gratification, because they are unable to live selflessly for the sake of the mission of the institute or society. As a canonist, I agree with her because there could be very serious canonical problems later on. In making such a decision, a superior would be exercising the vigilant care which is stated in canon 642.

8. *Code of Canon Law*, p. 65.

9. Canon 627 specifies that superiors are to have their own council according to the norms of their constitution.

10. All major superiors of clerical religious institutes of pontifical right, as well as clerical societies of apostolic life of pontifical right, are considered ordinaries. They have the right to issue dimissorial letters in accord with canon 1019. Such letters recommend the candidate's worthiness to the ordaining bishop in accord with canon 1015. They address the completion of the formation program and the fulfillment of all binding legal norms in accordance with canon 1020. In accordance with canon 1051, one of the testimonial letters which is included in the packet is from the rector of the seminary or house of formation about the state of the candidate's physical and psychic health.

11. *Code of Canon Law*, p. 216.

***Ethical, practical and even financial issues come into play
when forming HIV-related admissions policies.***

Developing admissions policies regarding HIV

by Jon Fuller, SJ, M.D.

During the first two decades of the U.S. AIDS epidemic numerous news reports, essays and even biographies of affected individuals brought considerable public attention to HIV infection among clergy and religious. This led religious orders and dioceses to engage in research, discernment and eventual policy development regarding HIV testing of applicants. Although no systematically-collected statistics on the number of HIV-infected clergy and religious are available, experience suggests that new AIDS diagnoses in this group are considerably fewer than a decade ago. However, individuals already known to be infected do occasionally apply to seminaries, and questions about accepting such candidates—and about universal screening of all candidates—remain active issues for vocation and formation directors.

HIV testing of candidates is a complex topic for many reasons. These range from understanding how new treatments have changed the prognosis of being HIV-infected, to appreciating the implications of testing from the perspectives of justice and canon law. This article attempts to provide a broad overview of these topics for those responsible for developing and carrying out HIV-related admissions policies.

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Three basic approaches to policy on HIV testing are in use today: 1) screen all applicants for HIV infection and exclude those who are HIV-positive; 2) screen all applicants, but use HIV-antibody status as only one of many important pieces of information; and 3) do not test for nor take known HIV-antibody status into account when considering an applicant.

If screening for HIV infection takes place, it is usually done at the time of admission to a seminary or religious order. Occasionally individuals are retested at later stages in the formation process, e.g., before deaconate or priestly ordination, or before admission to advanced studies.

Public policy approaches to testing

HIV testing in the context of admission to seminaries or religious orders raises in a specialized context a variety of questions which have already been given considerable attention in civil society. Because a positive HIV test can have potentially devastating psychological implications, and can also result in many forms of *de facto* (if illegal) discrimination (in housing, employment, and insurability), public policy has in general permitted HIV testing only when voluntary consent has been obtained. Exceptions to this general principle do exist. For example, in some localities emergency personnel (“first responders”) who sustain a potential occupational exposure to HIV can request HIV testing of a source patient without consent; federal and some state prisoners have been tested for HIV without consent; applicants to Job Corps (a federal job training program) are routinely HIV-tested; military personnel are routinely screened for HIV infection, and HIV-positive persons are barred from combat duty (where concern for battlefield transfusion safety provides a rationale). State Department employees being

posted to certain foreign destinations are also regularly HIV-tested (reportedly due to concerns about the non-availability of sophisticated medical services in some locations). Apart from these exceptions, HIV testing cannot be used by a municipality, school or employer as a means of discriminating against students, employees or prospective employees.¹ No other occupations are permitted to ask about or routinely exclude HIV-positive individuals (although HIV-positive surgeons who perform invasive procedures are counseled to work with local experts to maintain the highest safeguards for patients).

The U.S. bishops have concurred with this trend in public policy which opposes any discriminatory use of HIV testing, or the loss of employment because of being HIV-infected. In *The Many Faces of AIDS*, the Administrative Board of the National Conference of Catholic Bishops (NCCB) wrote in 1987: "We oppose the use of HIV-antibody testing for strictly discriminatory purposes.... There may be sound public health reasons for recommending the use of the HIV-antibody test in certain situations, either because some persons have a heightened risk of becoming infected or because precautions may have to be taken by others (e.g., prospective spouses, hospital staffs) if the tests are positive. Nevertheless we agree with many public health authorities who question the appropriateness

and effectiveness of more sweeping proposals such as widespread mandatory testing. It is critical that persons with AIDS continue to be employed as long as it is appropriate. The Catholic Church in the United States accepts its responsibility to give good example in this matter."²

In 1989 the full membership of the NCCB commented on HIV-related discrimination in their letter, *Called to Compassion and Responsibility*: "A growing body of legislation considers the individual with HIV a handicapped or disabled person. In 1978, in a statement on the handicapped, we said: 'Defense of the right to life ... implies the defense of other rights which enable the handicapped individual to achieve the fullest measure of personal development of which he or she is capable'" (*Pastoral Statement of the U.S. Catholic Bishops on Handicapped People*, November 15, 1978, No. 10).³

Arguments in favor of HIV testing

When moving from a consideration of antibody testing in civil society to the question at hand, one can appreciate that the process of applying for admission to a religious order or diocese has no precise parallel in the public sector. For example religious orders (and to a lesser extent dioceses) become responsible for the

Fact and fiction about HIV-AIDS

Myth: HIV infection is easy to transmit. Outside of health care settings, consensual behavior such as sexual intercourse or sharing of drug injection equipment is necessary to transmit HIV infection. The virus is not easily transmitted through such behaviors as coughing, sneezing, kissing, shaking hands, sharing food utensils or sharing common facilities such as bathrooms, dining rooms or water fountains.

Myth: HIV drugs eliminate the virus from the body. Although HIV medications can suppress the level of the virus to below detectable limits in the bloodstream, no treatments currently available eradicate HIV completely from the body.

Myth: All persons living with HIV infection will have a shortened lifespan. Not all persons who become HIV-infected develop AIDS. Even for persons who have an AIDS diagnosis, the use of anti-HIV drugs can lead to reconstitution of the immune system, the resolution of symptoms, and the capacity to live a normal life span without significant disability.

Truth: HIV drugs can cause changes in body shape. Some drugs are capable of causing a condition called "lipodystrophy," which can be manifested as loss of subcutaneous fat in the face and limbs and/or increases in fat in the neck and abdomen. Some of these drugs can also lead to increases in the levels of fat in the bloodstream (such as LDL cholesterol and triglycerides, both of which are risk factors for developing cardiovascular disease).

—Jon Fuller, SJ, M.D.

health care and living costs of their members for life, while this would not generally be true for the government or a business.

HIV-related costs are burdensome. Given the potential for a life-long relationship with the order or diocese, those responsible for the group's financial health might well be concerned about the potential impact of caring for an HIV-infected member. Published estimates during the 1980's and 1990's for the cost of providing medical care to one person with AIDS from the time of diagnosis until death ranged from \$23,000 to \$168,000, with much of this outlay representing the cost of hospitalization.^{4,5} While it is true that hospitalizations are much less frequently needed today because

Since HIV disease could make it impossible to engage in apostolic activity, a legitimate interest in the group's apostolic viability argues in favor of HIV testing of candidates.

of the success of current therapies, anti-HIV medications (needed for patients with evidence of significant damage to the immune system) can cost in the range of \$10,000 to \$25,000 annually.⁶ While this magnitude of expense is not exceptional for a serious illness, religious groups do not generally anticipate such outlays for their younger members. For this reason, some argue that it is quite reasonable and even necessary for religious groups to be cautious stewards of their finite resources by using HIV testing to eliminate those applicants who might develop costly illness or require long-term use of expensive medications to prevent such illness.

Can the candidate take part in the apostolate? A second argument frequently proposed in favor of HIV testing of applicants relates to the sometimes lengthy period of preparation needed to fully train a candidate for the group's work. Since religious orders and dioceses expect that their candidates will (with reasonable predictability) be able to healthily sustain themselves during the rigors both of formation and of later apostolic work, and since chronic disease or life-threatening illness could prejudice this capacity, apostolic groups have traditionally paid attention to health

considerations in evaluating the aptness of a candidate for the group's ministerial life. Since HIV disease could make it impossible to engage in apostolic activity, a legitimate interest in the group's apostolic viability argues in favor of HIV testing of candidates. In support of this position, canon law notes that questions about physical qualities and health are appropriate when selecting candidates for major orders: "After all circumstances have been taken into account in the prudent judgment of the proper bishop or the competent major superior, only those should be promoted to orders who have an integral faith . . . and other physical and psychological qualities which are appropriate to the order to be received" (Canon 1029, Requisites for Orders). Canon law also states: "As regards the inquiry concerning the qualities required of an ordinand, the following prescriptions are to be observed: 1) a testimonial is to be furnished by the rector of the seminary or the house of formation concerning the qualities required for the reception of orders; that is, the candidate's correct doctrine, genuine piety, good morals and his suitability for exercising the ministry; and, after a duly executed inquiry, the state of his physical and psychological health" (Canon 1051, Pre-ordination Inquiries).⁷

Objections to testing

In contrast to these arguments in favor of HIV testing for reasons of economics or apostolic availability, several concerns have been raised against policies that mandate screening.

Exclusion as a "medical condition" must be carefully considered. Although the notion of screening for serious medical illness in applicants is inherently logical and is supported in canon law, the definition of precisely what constitutes an excluded condition is unclear. In my experience of raising this question with those in leadership, there does not appear to be a commonly agreed-on sense of what should make any diagnosis excludable, nor a readily available list (even in a given religious order or diocese) of those conditions which are currently grounds for non-acceptance. In addition, circumstances change over time. Some conditions previously disallowed may be considered in a different light due to subsequent advances in available therapy. For example epilepsy and tuberculosis historically led to automatic exclusion, but the availability of excellent treatments for both make such conclusions illogical today. Similarly since current therapies for HIV infection make a normal lifespan and fully active life quite possible, it is not necessarily true

that being HIV-infected would prevent someone from contributing fully to the apostolic life of a religious order or diocese. If a group is considering defining HIV infection as an excludable medical condition, it is suggested that this be done in a manner that establishes consistent criteria for all excludable conditions. This would avoid the inconsistency of refusing HIV-infected persons while admitting candidates with other conditions that could also represent significant economic and availability risks to a group (such as those who have poorly controlled hypertension or diabetes, are heavy smokers, are morbidly obese, etc.).

If a group is considering defining HIV infection as an excludable medical condition, it is suggested that this be done in a manner that establishes consistent criteria for all excludable conditions. This would avoid the inconsistency of refusing HIV-infected persons while admitting candidates with other conditions that could also represent significant economic and availability risks to a group.

HIV infection does not presume that disease is present. Canon law does allow for exclusion of candidates who are not in good health, but it is quite possible to be HIV-infected and in an excellent state of health, with no diminishment of function or evidence of immune compromise. It has been argued that “health” as defined by the canons can be interpreted both as an absence of illness and as the capacity to carry out the demands of everyday life and work.⁸ Since some individuals with HIV infection may never develop AIDS, and since, with currently available treatments, many will be able to live fully productive lives, it is conceivable that excluding candidates who are merely HIV positive is not justifiable by those canons that consider a candidate’s current state of health. This argument suggests that exclusion for reasons of poor health would have to be based on more than one’s simply being HIV-infected, i.e. exclusion would need to be based on a more extensive medical evaluation to ascertain the presence of (or likelihood of developing) illness or serious immune compromise.

While the U.S. bishops have commented that “it may be appropriate for seminaries and religious communities to screen for the HIV antibody,” they have also expressed the opinion that HIV infection in itself should not be grounds for exclusion: “The point here is not to automatically exclude a candidate who is HIV positive,” the bishops state, “but rather to discern carefully this person’s present health situation as well as future health prospects; and thus to make an overall moral assessment of an individual’s capacity to carry out ministerial responsibilities.”⁹

Canon law gives high regard to individual privacy. Does canon law allow for the invasion of privacy necessary to ascertain the HIV status of candidates? According to canon 220, “No one is permitted to damage unlawfully the good reputation which another person enjoys nor to violate the right of another person to protect his or her own privacy.”¹⁰ In this light, it has been questioned whether the possible violation of confidentiality that could accompany routine HIV testing should preclude its use. In one view ascertaining a candidate’s HIV status is seen as an appropriate exercise of the bishop’s or community’s authority to evaluate candidates, and testing should be carried out with particular attention to confidentiality of all records: “The diocesan requirement in question (to test candidates for HIV antibodies) is a legitimate one. The bishop, charged with obligations regarding seminary admissions and promotion to orders, can decide to require testing for this admittedly serious disease. The diocesan policy, however, should insure that the results of any testing are kept confidential and are shared only with those charged with ultimate responsibility for seminary admissions and then only with the explicit written consent of the candidate.”¹¹

However, in another view, the potential impact of HIV testing, and the difficulties inherent in maintaining absolute confidentiality of test results, argue against a policy of screening for HIV. One observer writes, “(Because testing) opens a wide window of vulnerability—psychological, social, economic—for an individual against which the seminary and diocese can guarantee only limited protection . . . the need for a seminary to screen out HIV infected persons is not compelling enough to outweigh the established right of a person to protection against potentially damaging intrusion of privacy.”¹²

The church has criticized others who exclude the HIV-infected. Since both public health and national church authorities have criticized mandatory testing of

Basic medical facts about HIV/AIDS

The HIV epidemic has been recognized since 1981, when unusual tumors and infections were identified among patients in Los Angeles, San Francisco and New York. In 1983 the epidemic was recognized as being caused by a virus which initially spread to the human population from chimpanzees. The virus is known as HIV (human immunodeficiency virus). Adults can become infected with HIV during sexual intercourse, from sharing injection equipment during intravenous drug use, from transfusions (if blood is not tested for HIV), and rarely from occupational exposure (such as needle-stick injuries in medical contexts). HIV-infected pregnant women can pass the virus on to their children during intrauterine development, at the time of delivery or during breastfeeding.

Adults recently infected with HIV may experience the “acute HIV syndrome” consisting of symptoms such as fever, rash, sore throat, and swollen lymph nodes. These characteristically occur within a few weeks after HIV infection and may last for a few days to a few weeks. Subsequently the individual enters into a period of having no symptoms at all, a phase which may last for many years. During this time the person neither feels nor looks ill, and apart from HIV testing, there is no way to know that this person is HIV-infected and is capable of passing on the virus.

The fundamental problem caused by HIV infection is that it attacks CD4 cells (also known as T cells or helper cells). These cells are a critical component of the human immune system, and orchestrate the response of the immune system to infections. In most HIV-infected persons, the CD4 count gradually decreases, making the immune system vulnerable to numerous conditions known as “opportunistic” diseases (so named because they only occur in the context of immune compromise.) These may include numerous infections, tumors, neurologic disease or “AIDS wasting syndrome,” a gastrointestinal condition manifested as fevers, wasting and diarrhea.

Within six weeks to six months after becoming HIV-infected, antibodies against the virus are produced by the immune system and can be detected in the blood; these are the basis of the HIV test. Since these antibodies are present in blood serum, those who are HIV-positive are also known as being “seropositive.” A diagnosis of AIDS (as compared with only being HIV-positive) occurs when someone who is HIV-infected develops one of the clinical conditions noted in the preceding paragraph, or develops a CD4 count less than 200. A diagnosis of AIDS represents significant disease or immune compromise as the result of HIV infection. Although the majority of untreated, HIV-infected persons will eventually develop an AIDS diagnosis, a small number of persons have immune systems which are able to fight the virus even without the benefit of drugs.

Since 1996 the simultaneous use of three drugs against HIV (a combination or “cocktail” known as HAART: Highly Active AntiRetroviral Therapy) has revolutionized the care of HIV-infected persons. HAART is capable of suppressing the level of HIV in the bloodstream to below detectable levels, and is also capable of reconstituting the immune system (as manifested by a normalization of CD4 counts and resolution of opportunistic diseases). HIV-infected persons are generally started on these drugs many years into the average course of HIV infection, if and when the viral load or CD4 count indicate it. Persons who meet criteria for initiation of anti-HIV therapy and who are started on these medications may live for a normal lifespan if they are able to normalize the CD4 count and suppress the virus completely. However, if persons taking these drugs are not vigilant about missing doses, HIV may develop resistance to these medications, leading to difficulties in maintaining complete viral suppression and in restoring immune function.

Persons who are taking HIV therapies do have to contend with potential side effects and toxicities, although more recent drugs attempt to minimize these toxicities. Persons living with HIV infection are able to live in community without endangering others, and if their condition is well controlled, may be capable of fully engaging in a community’s apostolic works.

—Jon Fuller, SJ, M.D.

civilian populations, some have wondered whether the church or its organizations are hypocritical if they test while teaching that others should not. From a global perspective, an analogous question can be raised. Given the inexorable spread of HIV infection, especially in developing countries, would it be desirable or even possible to “keep HIV away” from orders and dioceses in these areas? Could such an intentionally

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screened clerical or religious group effectively witness to populations where up to 20 or even 35 percent of adults are HIV-infected?

Rejecting seropositive candidates overemphasizes performance. Some view it as ironic that corporations are not allowed to screen their employees for HIV infection, but the church’s orders and dioceses—established on principles that reject a utilitarian analysis of human worth—are sometimes doing so. Excluding candidates who, for health reasons, might contribute for a shorter time to the group’s apostolic endeavors can appear to place a greater reliance on an individual’s capacity to perform work than on a recognition of the genuine call of an individual to the life and mission of the order or diocese. Some would further argue that given the global extent and unprecedented impact of the AIDS epidemic on the human community, it is certainly plausible that God could call to religious or priestly life some persons infected with HIV. In the same manner that vowed life witnesses to a profound confidence in God’s providence, is it possible that the HIV/AIDS pandemic challenges the church to bear witness to the Gospel’s inclusivity in the context of a global struggle with this widespread infectious agent? It is worth noting here that many religious groups have experienced that individuals with particular disabilities (e.g., deafness, blindness or other physical handicaps) can also have vocations to religious life or priesthood, and frequently possess the capacity to

perform ministry with selected populations in ways that are not possible for non-disabled individuals. Religious orders with HIV-positive members have witnessed this particular ministry *ad extra*, as well as to members of their own communities.

The HIV test should not be used as a surrogate test. Some have raised a concern that HIV antibody testing, ostensibly to exclude a serious medical condition, might actually be used as a surrogate means to test for past homosexual activity, or for past history of injection drug use. Since there is no necessary connection between HIV infection and homosexuality or drug use, using the HIV antibody test in an attempt to identify either of these personal characteristics would be both inaccurate and unjust.

Does testing candidates for HIV affect the group doing the testing? In an important review of the foregoing questions, moral theologian James Keenan has raised the foregoing question in an article in *Review for Religious*. Exploring the concept of maintaining purity within religious organizations, he suggests the possibility that HIV testing may be considered not so much to exclude disabling illness as to insure the relative “purity” of the group by forbidding certain conditions. He also questions what the limits of such an approach might be as he anticipates the next generation of genetic tests, based on the human genome project, that will identify increased propensity to develop a broad array of diseases.¹³

Adopting a testing policy

This discussion of antibody testing of candidates for religious orders and dioceses reveals the number and complexity of issues involved. While cogent arguments can be made in favor of HIV testing for reasons of economics and apostolic availability, a number of counter-arguments raise serious objections to a protesting approach, especially if the policy excludes on the basis of HIV-infected status alone (i.e., without consideration of the specifics for each individual case). Given this situation, is there a single appropriate position to take? How should a group go about developing its policy?

The processes by which different groups have developed their HIV testing policies vary widely. In some, policies have been developed after a wide consultation with members and experts over months or even years. In others, the policies of another group have been used “as is,” or after minor adaptations. In some circum-

stances a decision to screen applicants for HIV has been made without having a clear understanding of the meaning of being HIV-infected, or without a plan of action in the event that an HIV *positive* applicant is encountered.

While it can be invaluable to review testing policies developed by other groups, the complexity of the issues involved suggests that there is no substitute for each group engaging in a prayerful and thoughtful discernment of the question. Simply adopting another organization's approach prevents the organization from reflecting on the challenges to which it must respond

While it can be invaluable to review testing policies developed by other groups, the complexity of the issues involved suggests that there is no substitute for each group engaging in a prayerful and thoughtful discernment of the question.

from its own perspective, and it also bypasses an opportunity for critical reflection on the group's general criteria for admission and its unique mission in the church. It is suggested, then, that each organization invest in the process of working through these questions in its own circumstances. After consulting with experts and other groups in similar circumstances, the members can fashion their response based on an understanding of relevant *current* scientific and ethical data applied in the context of the group's unique characteristics, including its finances, history, personnel and charism.

Recommendations

If a policy to employ antibody testing is made, the following recommendations are offered.

If some candidates are to be tested, all should be tested. Although a group might want to selectively test those applicants who report what it considers past "high risk" activity for HIV exposure (e.g., homosexual orientation or activity, blood transfusion, intravenous drug use), if knowledge of HIV status is the goal

of testing, justice suggests that the same criterion be applied to all.

If candidates are to be screened for HIV antibodies, the test result could be considered a significant part of that candidate's overall profile without necessarily precluding consideration for entrance. Orders and dioceses have historically admitted candidates with certain medical problems, believing that even persons with health risks can have vocations. To accept an HIV-positive applicant would clearly involve accepting the probability of increased medical and financial liability. On the other hand, a positive HIV test is not absolutely predictive that serious disease will develop, especially since the development of currently available treatments. For those found to be HIV-positive, a detailed clinical evaluation by an HIV-experienced physician could be obtained. This would help locate the individual along the continuum of the natural history of HIV infection.¹⁴

If being HIV-infected is automatic grounds for exclusion, it is recommended that HIV testing be done early in the application process. It seems only fair to applicants that the group's testing policy be made clear from the outset, and that HIV testing be done as the first step (or as a very early step) in the application process if its results are determinative. There is no need to put applicants (and the group) through other parts of the admission process only to tell applicants later that they would never have been considered had their HIV status been known earlier.

If an order or diocese requires HIV antibody testing of candidates, it is responsible for maintaining the confidentiality of all results reported to it. Local law may require that the applicant designate in writing the individual(s) to whom test results will be released. Disclosure of test results to other individuals or agencies, or failure to protect against inadvertent release of such information to other individuals or agencies, could create significant legal liability. Agencies have been successfully sued for loss of confidentiality when the results of HIV tests have been divulged without explicit written consent. Policies regarding precisely which individuals will learn HIV test results, who will be responsible for maintaining confidentiality, where records will be stored, and how long test results will be kept for both rejected and retained candidates, should all be determined before testing begins, and this information should be available to applicants. (See the box on page 10 for a resource on archiving medical information.) The results of prior

HIV antibody tests which are freely offered by a candidate must be treated with the same strict confidentiality.

If an order or diocese is instrumental in a candidate's being tested, and if the test becomes grounds for the candidate's exclusion, the group must consider sharing some responsibility for the eventual impact of that test result on the individual's life. Groups that require HIV testing of candidates must insure that the candidate is aware of all possible implications of learning that one is HIV-positive before testing occurs (e.g., its potential, if illegal, impact upon housing, employment and both life and health insurability). The group should also consider its responsibility to assist the individual in adapting to the news of learning that one is HIV-infected, including helping to bear the costs of counseling if this is necessary.

Devising admissions policies in regard to HIV antibody testing is far from simple. However doing so can head off many potential problems. A proactive stance that anticipates and prepares for the possibility of HIV-infected candidates (or longstanding members) through ongoing educational programs and policy development can defuse crises and guarantee well thought-out policies. Never creating HIV-testing policies leaves a community or diocese in a reactive and crisis-oriented mode. Those in authority will be well served to avail themselves of qualified consultants, to move carefully but deliberately in developing policy, and to be mindful of the need to frequently review and revise all related policies and procedures. †

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Both of these diseases can significantly affect a person's life, but treatment and medication can make a world of difference.

How MS or epilepsy could affect a candidate to religious life

***HORIZON* interviews Daniel R. Wynn, M.D. and Cathy Meyer, R.N.**

What is multiple sclerosis (MS)?

MS is an autoimmune disease in which the body's own defense system attacks myelin, the fatty insulation that protects nerve fibers in the brain and spinal cord. The damaged nerves may form scar tissue (sclerosis). When any part of the myelin sheath or nerve fiber is damaged or destroyed, nerve impulses to and from the brain are distorted or interrupted. As such it can affect every system in the body.

Are there different levels of MS?

Yes. MS affects people according to which of the three main classifications they have. The most common type, affecting 85 percent of patients at the onset, is *relapsing and remitting MS*. This occurs typically in younger adults, from their early 20s into their 40s. The symptoms are mild about half the time, and they come and go. Patients experience flare-ups of symptoms for maybe a week or two, and then they diminish. The relapsing and remitting type of MS could last for

years—perhaps 30 or 40 years even—but eventually the majority of people move on to *secondary progressive MS*. These patients occasionally have acute flare ups, and over time they gradually get worse. Finally, in *primary progressive MS*—occurring in 12 percent of patients, usually over age 50—patients don't pass through a relapsing and remitting stage. There are no flare-ups, just a gradual worsening of the symptoms.

What are the symptoms?

The symptoms of MS include tingling, numbness, painful sensations, slurred speech and blurred or double vision. Some people experience muscle weakness, poor balance, muscle tightness or spasticity. These symptoms may be temporary or permanent. Problems with bladder function are a concern for many. While there are many symptoms, most of them can be managed well, and usually they don't all occur at the same time. Most patients experience these symptoms as short-term flare-ups. That said, here are the most common symptoms.

Daniel R. Wynn, M.D. is a physician board certified in neurology, clinical neurophysiology and EEG, EMG and neuromuscular disease, and sleep disorder medicine. He is a member of the American Epilepsy Society and director of clinical research and co-director for Consultants in Neurology Multiple Sclerosis Center, located in Northbrook, IL. The center conducts clinical research and provides patient care, and it is an affiliated chapter of the National Multiple Sclerosis Society.

Cathy Meyer, R.N. is a registered nurse with over 30 years of experience. For the last eight years she has been the lead research coordinator for Consultants in Neurology Multiple Sclerosis Center in Northbrook, IL.

Fatigue Eighty-eight percent of MS patients suffer fatigue. For this reason, careful time management skills, such as getting important tasks done early in the day, may be important for maximum productivity. Fatigue may involve strength, such as walking through a grocery store, or cognitive functioning, such as memory or administrative skills.

Walking problems These affect 87 percent of patients. They have trouble walking because of muscle tightness, fatigue, lack of balance or dizziness.

Cognitive problems These affect 65 percent of MS patients; they experience weakness in memory and processing. Patients can forget everything from how to spell simple words to how to do their jobs. Fatigue

and cognitive problems are the most common reason MS patients lose the ability to work.

Urinary or bowel dysfunction Abnormal urgency and frequency of urination or defecation occurs in the majority of patients.

Pain or sensory problems Numbness and pain can affect hands or feet and occur in 60 percent of patients. Numbness in the feet can make it hard to walk; numbness in the hands could prevent people from using a computer because they can't feel the keyboard.

Visual disturbance Fifty-eight percent of MS patients experience episodes of optic neuritis, characterized by decreased sight associated with pain with eye movement.

How is MS treated?

There are presently five federally approved drugs to treat MS that have been shown to slow the natural progress of the disease. These therapies are injectable drugs, and we teach patients to give themselves the shots at home. In addition many treatments effectively alleviate the symptoms of MS. We're able to manage symptoms with these medications, physical and occupational therapy, diet and exercise. Finally, flare-ups can be managed with an IV infusion that we do in our office.

Research is moving at an unbelievable pace, and we think that in our lifetime there will be a cure for this disease; so slowing it down is important.

What is the prognosis for someone with MS?

You simply can't generalize about it. The disease ranges from mild and intermittent to steadily progressive. Some patients have few attacks and little, if any, disability. At diagnosis, 85 percent of patients have a relapsing remitting course, meaning they have attacks followed by periods of partial or even total recovery. Fifteen percent of patients experience progressive disease from the onset. The course MS takes and the timeframe for its progression are different for every patient and unpredictable for every patient. Experts agree that early therapy gives individuals the best chance at a more mild disease course.

It sounds like a pretty overwhelming disease. How could a person with MS carry out ministry or be an active member of a religious community?

Many individuals on therapy will have little observ-

able disability to others. The time course of the illness varies markedly from person to person, with some individuals going many years between flare-ups. There *can* be a lot of symptoms, but fortunately we have good symptomatic treatments. We care for many MS patients who are doctors, lawyers, judges, even a few professional actors and athletes. The impact of MS is different for each person. We encourage our patients to make a plan and build a team. The plan is how they're going to manage their disease, and the team is the people who will support them in carrying it out. Their team might include family members, loved ones, doctors, therapists, trainers, etc. The more successful patients are at building a team, the more successful they may be in achieving personal goals.

The time course of MS varies markedly from person to person, with some individuals going many years between flare-ups. There *can* be a lot of symptoms, but fortunately we have good symptomatic treatments.

Also I've found that successful MS patients look at life differently. I think they appreciate life a little more because they live with a chronic illness, and as such, they have tremendous compassion toward others with a disability and show a lot of kindness. I think MS patients are a really great group, and I feel privileged to work with them.

EPILEPSY

What is epilepsy?

Epilepsy is a disease characterized by recurring seizures, which means a temporary loss of body control. While commonly starting in childhood, it can come on at any time in life. Epilepsy can be secondary to a brain injury, such as a tumor, stroke or trauma. The majority of cases are idiopathic, i.e. without known cause.

Is there a range of severity?

Yes, like MS, epilepsy is a variable illness. The majority of cases are well controlled with medication, and the patients have no apparent symptoms in between

seizures. Individuals well controlled on medication may go many years between seizures, and in some circumstances, be able to go off of medication.

How does it affect people?

There are several types of seizures. The most common is a partial seizure in which a small part of the brain is initially affected, resulting in loss of awareness with or without a stereotyped mannerism, such as twitching of the arm, leg or face. Usually these last for less than two or three minutes. They can even be as brief as 15 seconds. At times a partial seizure may spread to involve more widespread areas of the brain, resulting in a generalized seizure.

The medications have improved in the last several years, so that with treatment, most people with epilepsy can function normally.

A generalized seizure is less common. It involves a complete loss of consciousness and convulsions. Any type of seizure can be a danger in activities requiring careful vigilance, such as being on a ladder or a roof, driving or cooking. The frequency of seizures is vari-

able—as much as several times a day to once every several years. However the vast majority of individuals with epilepsy have no outward symptoms, and the disease would not be apparent to others.

Does epilepsy worsen as people age?

Epilepsy is not a disease that grows worse over time. It could worsen if a person had a stroke or a brain injury or was not careful to take medication regularly. Alcohol and irregular sleep can exacerbate the disease. However, most people see a great improvement once they seek treatment. The medications have improved in the last several years, so that with treatment, most people with epilepsy can function normally.

How is epilepsy treated?

People take medication, usually in the form of daily tablets. It's also important they watch their alcohol consumption, get regular sleep and visit their doctor regularly.

It sounds like a person with epilepsy who is following a treatment plan can easily live a full life of ministry and community.

Yes, very much so. The most important message I want to add is that there is a lot of prejudice against people with disabilities, including epilepsy. It used to be that we thought people with epilepsy were possessed by the devil. It's important to foster an environment where people can reveal these conditions, get the help they need, and be contributing members of society. +

A physician and former vocation director shares his experience in assessing—and sometimes accepting into his community—men with mobility problems.

Mobility issues in prospective members of a religious community

by Louis Lussier, OSCam, M.D.

Vocation recruitment has changed drastically since Vatican II, with today's candidates being older and having greater life experience. This shift has created new challenges in assessing candidates justly and effectively. Sometimes these more mature candidates approach us with health problems and physical limitations. In this article I'll address the issue of diminished mobility in candidates seeking entry to religious life.

As a member of the Order of the Servants of the Sick, I take a vow to care for the sick at the risk of my own health and life. Thus I feel a clear empathy for physically challenged men who seek admission to our order. I spent part of my life as a physician specialized in rehabilitation; this exposed me to the challenges such men face in rebuilding their lives and carrying out day-to-day activities. I've also served as a vocation director. Thus I bring all of these perspectives to the following presentation.

Challenge of decreased mobility

Our society has become more sensitive to issues concerning physically challenged people. When I began in the rehabilitation field, they were identified as "handicapped," then "disabled" and now "challenged." This evolution in terminology recognizes that we are

dealing with people who have had to readapt to functional and structural deficits in their mobility, while they remain persons with full human dignity and capacity to relate to others. This readaptation entails the maintenance and improvement (if possible) of the physical function and abilities they hold, the use of devices to supplement and augment their function, and the modification of their environment to help with challenging tasks.

Modern medicine has given a much longer lease on life to many people who would not have survived as long in previous eras, and it has permitted them to pass on their genetic flaws. This impacts religious communities since our members reflect the trends and patterns of disease in the general population. It impacts us also in our recruitment, through the inquiries of older and disabled candidates.

People may come to us with mobility restrictions secondary to trauma or caused by disease or congenital malformations. The trauma may be the result of road accidents, of sport or war injuries, of roughhousing or violent attack, of injuries in the home or work place. Many diseases can cause mobility deficits: amputation due to cancer, diabetes, infections, vascular blockage; muscle weakness due to polio, nerve damage, dystrophy, connective tissue disease; neurological conditions such as permanent deficits from head trauma or spinal cord injury, stroke, MS or other debilitating diseases; and various forms of arthritis affecting joints and spine, muscles and connective tissues. This list is not exhaustive but is given to illustrate that many conditions can affect mobility as it impacts the totality of one's health. We have to consider each deficit in mobility in context of the person's present health and prognosis for the future.

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Ability to engage in the mission is primary

Before I proceed I want to engage the debate between our desire to be compassionate and fair toward a challenged prospective member and our faithfulness to the mission of the congregation we serve. Our founder, St. Camillus, judged the fitness of a candidate by his ability to serve the sick. This was a physically demanding task in the 1500s. This is still the case today for those who do bedside nursing, although there are less physically demanding careers within our order, such as pastoral care. The mission of the congregation is the primary criterion against which to measure our policies about accepting candidates. If our mission is primar-

As we applied the criterion of the mission, we had to be attentive to our desire to rescue the applicant. It is a red flag when the applicant tries to convince us that we should accept him *because* he has a disability.

ily sitting in adoration before the Blessed Sacrament, as compared to going on foot into jungles to evangelize, our criteria for mobility will differ. We Camillians have approached physically challenged prospective members with a willingness to risk, and that has not always resulted as hoped. We have had to deny applicants in wheelchairs but have admitted men with cerebral palsy, amputation, mild-to-moderate deficits from lower limb injuries, and older men with degenerative joint disease. Their ministry had to be tailored to their abilities. We've had a few successes: three of five men who fit these descriptions completed the formation program. Two are still with the order; the other later incardinated with a diocese.

I consider this track record solid justification to continue our approach toward candidates with locomotor handicaps. As a health care order, constantly rubbing elbows with other professionals and workers in this field, I find it imperative that we consider people who may suffer from mobility deficits but who can teach us from their experience and may relate to our clients with a unique sensitivity acquired through their strug-

gle with physical limits. The greatest impact has been on the people we serve. Having physically challenged members gives our Camillian witness greater credibility because we try to live it inside the community. But without a well-defined criterion focused on mission, we can be seen as guilty of discrimination or, on the other hand, spend much energy where there is little hope of success.

As we applied the criterion of the mission, we had to be attentive to our desire to rescue the applicant. It is a red flag when the applicant tries to convince us that we should accept him *because* he has a disability. We also had to confront our biases, aversions, and prejudices.

Another hurdle in applying this criterion is the adaptation of the community's lifestyle to accommodate this challenged person. This may trigger negative reactions that result in the applicant leaving, wounded by the experience of the community's rejection. Such issues as preferential location of the room, distribution of lighter household tasks, and other allowances for the disabled candidate may be seen as unmerited privileges and resented by other community members.

Our older and smaller residential facilities are typically not adapted for people with disabilities. We would not want to undergo substantial costs to our houses until we know it is for the long haul. Some of our residences for retired members are handicap-accessible and theoretically could be used for a disabled applicant. But this situation does not fit the goals of the formation program, since the purpose of these facilities is to care for older members. The formation of new members in such a setting would take a back seat to the purpose of the residence.

History and assessment of the candidate's mobility challenge

Thus, having determined our mission criterion and our willingness to receive a disabled person in our community and formation facility, we then have to assess each candidate in terms of present and future demands. A disability is not stationary: it augments as we age; it exposes us to further injury; it can be a cause of further dysfunction through pain, inflammation, degeneration, and strain placed on other body structures and systems. A solid history of the disability and of the person's adaptation to it is essential. I look for use of drugs, frequency of visits to physicians and numbers of surgeries, to see if the person has made the disability a crutch to avoid living. A consultation with a reha-

bilitation professional or team may prove useful to determine what the candidate and community face.

If specific diseases have caused the disability, such as polio, these must be assessed medically for a prognosis. With polio, people who are barely functional walkers at age 35 may be wheelchair-bound by age 50. In cases where diseases like diabetes are at fault, the decision is made not on the disability per se, but on the total health of the person with the diabetes. A condition such as severe obesity accelerates the breakdown of health, which impacts the disability and augments its severity; obesity is often linked to decreased mobility.

As a rule, those born with disabilities are better integrated than those who acquire them, assuming they have been raised in a climate of acceptance. The more the individual had invested in a self-image based on physical performance (in sports, hobbies or other physical leisure), the more difficult and lengthy the adjustment is.

Each cause of disability has its implications: a back injury can lead to surgeries and much time lost due to repeated episodes of back pain. A leg injury with a limp can lead to chronic back problems, which then cause further immobility. Suffice it to say we have to assess each situation realistically with the candidate. We want the individuals to be part of the decision because they will have to live with the consequences of admission to a religious order with their mobility restrictions. The consequences may not be favorable and could bring about failure to continue in religious life.

It is our policy to deny any man who has a chronic condition that can deteriorate and manifest itself as a debilitating condition. We've turned away several men with Crohn's disease, as this progressive illness can be associated with debilitating arthritis. On the other hand, we have accepted older candidates who showed mild evidence of arthrosis, or degenerative joint disease, and eventually underwent successful joint replacement surgery.

We have also accepted a member with cerebral palsy affecting principally the lower limbs. He was completely independent in his personal needs and needed only adaptation for driving a car. Anyone who would need ongoing assistance in daily living would be denied entry into our order.

I have come across a religious-order priest who was blind and had entered his order as such. He was independent and well adjusted to his disability. He needed assistance when moving around on unfamiliar terrain. He contributed greatly by his insights and perspectives as a man without external vision.

Adjustment to the disability

The blind priest introduces an important component when deciding to admit a physically challenged candidate. The question pertains to the person's adjustment to his or her disability. A more recently acquired limitation implies that there is still a lot of work to do to adapt. Even when the physical rehabilitation is completed and the person has mastered skills to compensate for the loss of function, there is much to do to adjust mentally and relationally. As a rule, those born with disabilities are better integrated than those who acquire them, assuming they have been raised in a climate of acceptance. The more the individual had invested in a self-image based on physical performance (in sports, hobbies or other physical leisure), the more difficult and lengthy the adjustment is.

Characteristics of poor adjustment—anger, resentment, shame, isolation, risk-taking behaviors, rebellion—may await a time when the person's guard has been lowered before they are expressed. Passive-aggressive attitudes, new demands for special treatment, manipulations, even deceit are things I observed from some men in our formation program. I had to delve into family histories to grasp the dynamics I was observing in some candidates. I had to assess as best I could whether their risk-taking behaviors had contributed to their injury or trauma. If so, I had to look for whether such behaviors continued because they could lead to further injury and disability.

For any candidate, and particularly for a disabled applicant, a good testing ground for us has been the health care setting of our nursing home, where our own lay nursing and administrative staff observe prospective members and give us an evaluation of their performance and attitude. I have noted that disabled men entering the order were more likely to reveal their

maladjustment in these circumstances, outside the confines of the community. Working with the sick and among medical staff brings out one's true colors.

Another aspect of adjustment to a disability is the individual's spirituality. How do candidates see their experience and disability as part of their journey, especially their spiritual journey? How has this experience graced them? A young man who had sustained a neck injury in gymnastics, resulting in quadriplegia, told me that this change in his life brought him to the discovery of Jesus Christ. He would not trade his new relationship with Christ even for a full recovery from his disability. The blind religious priest had gone a long way, to new sight, sight in the spiritual realm.

It would seem simpler and more prudent to choose a criterion of absence of physical disability. It would avoid a lot of difficulties. Yet something would be lost.

These elements are critical, as people will minister out of their experience of disability. We can observe them with the sick and see their sensitivity to the suffering of others. One candidate did nothing but joke around with the sick and about the sick (this is how he coped); he still felt bitter about his own condition. Our mission imposes not only physical demands but also the relational and spiritual demands of ministry.

Implications for the community

With the decision to accept a person with mobility impairments, we accept the long-term implications. These will include deterioration of function and increased dependence for the disabled member and a financial burden for the community. Everyone's level of function diminishes with age, particularly after age 60. The smaller our reserve, the earlier we begin to feel the effects of this loss. We have to plan for this when we have members with mobility deficits. They would have prepared for a deterioration in function in a life outside community; we have to provide for them in the same way in community.

This loss of function leads to greater dependence, which may mean a special environment, such as assisted living, is needed sooner than most people would need it. It may mean special apparatus, such as motorized chairs. It may mean personnel to assist with morning and evening rituals. These factors have to be considered, at least as possibilities, when the person is evaluated as a candidate.

These factors also imply cost: remodeling, equipment, prosthetics and orthotics, surgeries and medical care, special training, at times, for career options, and so on. Some costs may not be apparent at first, such as the costs associated with severe obesity (including adapted furniture, larger vehicles and delayed medical consequences of the obesity). The impact is felt as health care expenses increase while income decreases because the person is less able to work.

It would seem simpler and more prudent to choose a criterion of absence of physical disability. It would avoid a lot of difficulties. Yet something would be lost. As a Servant of the Sick, I have so often been blessed by the embrace of the sick, by their witness of faith, by their insights and vision that oblige me to see in a new way. It is true of the religious who joyfully lives a life of faith and service with a disability. It is a powerful witness on the part of the individual and of the community who supports this person and ministry. Most disabled religious acquired their conditions after entering: they became ill or were injured and became disabled. The way we care for those among us most in need, whether they be battered warriors or disabled recruits, reveals much about the depth of our evangelical commitment.

In this day and age we cannot systematically turn our backs on brothers and sisters with mobility challenges who feel called by God to serve as religious. We need the poor to teach us poverty, and we need the sick to teach us humility and trust. When God brings to us a person who would join us, yet suffers from mobility restrictions, we need to explore the possible vocation with that individual respectfully and realistically. We need to be prepared and know what to look for so that the process of discernment can reveal the will of God to both parties. This is not only helpful but can be healing when the applicants have felt respected and welcomed into the process of discernment. ✚

***Pain that never disappears for good can take a big toll on a person.
If vocation ministers are evaluating a candidate with chronic back pain, it helps to
understand the many causes and the variety of treatments.***

Chronic back pain and the capacity to live religious life

by Daniel Hurley, M.D.

“Back pain” by definition refers to what most people would consider the low back, and thus is a rather specific malady and complaint. The span of medical diagnoses affecting the spine, however, can affect absolutely every part of the body. Chiropractors have long asserted that they can relieve a myriad of internal organ dysfunctions by simple targeted adjustments to the spine. This claim has been based on the fact that the body parts receive innervation from various locations in the spine. Well, it is not quite that simple, but let us look at how the spine is organized in the first place, how certain disease states or degenerative conditions or injuries manifest themselves, and how these may affect one’s life activities or even one’s vocation.

Basic anatomy of the spine

Essentially the spine is a flexible structure of stacked cylindrical bones, each separated by a rubbery cushion called a disc, as opposed to being one long stiff bone, such as in the thigh or the upper arm. A solid bone

would be good for skeletal support and muscle anchoring roles, but would not be all that helpful to the acts of moving, bending, twisting or reaching. The price for movement, however, is wear and tear and stress points for injury.

Looking at the spine from the side, one sees that it is shaped as a subtle double “s” curve. The neck and low back each should normally curve inward. The middle spine, in the region of the ribs and shoulder blades, and the very bottom region, below the belt to the tailbone, each curve outward. Extremes of either can occur with disease, injury or age and put overloads of stress on the joints, nerves and muscles.

The classic “poor posture” position usually involves sitting with head forward, rounded shoulders, and slumped back, such that the “s” shape of the spine is turned into a big “c” shape, which strains the low back and neck. In older women it risks thoracic compression fractures, and in everyone it eventually produces the stiff, hunched, smaller “little old man” or “little old lady.” On the other hand, overweight individuals with protuberant bellies have excess arching in the low back, straining the muscles and the small joints in the back of the lower spine.

The vertebral column is the bony component of the spine complex, and can be imagined as a stack of padlocks, with the ring portion towards the back, and in between each of the solid round portions the cushion of the disc. The rings in the back of this stack all line up one on top of the other to form the spinal canal, and it is through this vertical column that the spinal cord runs from its origin at the base of the skull down to the bottom of the spine in the sacrum, where by that point

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it is made up of only a few remaining strands of nerves. The rest of the nerve fibers have already exited the spinal canal along the way to reach the rest of the body.

The spine is composed of three regions—the neck, thoracic region and lumbar region—each of which contains segmental levels of bone and discs. Between each of these segments along the course of the spine are pairs of exit tunnels, one each to the right and left, which allow individual nerves to leave the spinal canal and reach various specifically mapped out parts of the body. These nerves have “motor” fibers which send instructions to various muscles, and they have “sensory” fibers which bring in sensation signals of various types from specific areas of the body.

A key issue in the medical evaluation of spinal disorders is to ascertain whether there is ongoing nerve injury or pressure, as opposed to more musculo-skeletal mechanical pain.

Muscles and ligaments attach to the spine and form both the support structure of the spine itself, as well as origins for the muscles of the shoulders and the hips, and head. The inner lining of the spinal canal consists of vertical cylindrical tubes surrounding the spinal cord from top to bottom. Filled with fat, fluid and blood vessels, these envelopes serve to cushion and nourish the spinal cord and delicate nerve structures. One can move and bend and twist without rubbing the nerves and spinal cord against hard rough edges.

What can go wrong with the spine

Now that you have an overall idea of the anatomy of the spine, you can better understand why it can be so vulnerable to pain and affect the body from head to fingertips to toes. It is a flexible rod made up of multiple movable segments, on top of which sits a rather heavy head (the weight of a small bowling ball). More often than not, we keep our spines in a posture of leaning slightly forward, since our eyes and arms—and thus our actions and tendencies—all focus forward and downward. This then places extra pressure on the

discs, while stretching and continuously straining the muscles and ligaments of the back of the spine. The discs have very tough outer fibers, being like miniature tires lying on their sides between the bones. Inside they have a thick gel which allows for a springy-ness and the ability of the spinal bones to tilt on each other and absorb compression. On the other hand, if too much pressure is loaded onto a particular disc, this gel can burst through a weakened spot in the outer “tread” of the disc—this is a herniated disc. Often enough this occurs right where there happens to be a nerve exiting its tiny tunnel, leading to the phenomenon we know as a pinched nerve, sciatica in the lumbar region, or radiculopathy in general.

Over time all discs wear down, much as break pads in a car or sponges in the kitchen. When this occurs, the little guiding, gliding facet joints in the back of the spine can become more stressed and altered in shape, leading to facet degeneration or arthritis. When the discs and facets and bones all change their shapes due to wear and tear, they can take up space in the areas where the nerves are supposed to be, and this narrowing of the nerve spaces is called spinal stenosis. Shrinking of the discs also leads to the forward bent posture of the elderly, and sometimes a sideways curving called scoliosis, which can be painful also.

Impact of spinal disorders on everyday life

Here are some quick rules of thumb for how problems with these spinal conditions may manifest themselves, and how they may affect what one can and cannot tolerate with regard to activities, work, self-care or recreation. Disc problems in the low back are generally worse in sitting or bending forward (in the neck often more with turning or leaning back). Facet joints are usually more painful with standing or leaning back or lying on one’s stomach. Stenosis is usually worse with standing or walking. Muscles can hurt in any position, but more often when they are being strained in the leaning forward position or coming back up from bending maneuvers.

Thus, someone with a “discogenic” pain problem is usually worse in what others would consider a restful position, i.e., sitting—in a car, at a desk, in a movie or on a soft, poorly supportive couch or chair. Facet arthritis makes it hard to do anything requiring a lot of prolonged standing or repetitive side-to-side twisting. Spinal stenosis can severely limit one’s ability to walk even half a block at a time. Muscle pain and disc pain

can make it nearly impossible to sustain simple, minimal forward-bent positions such as in cooking, doing the dishes, vacuuming, loading and unloading the trunk of a car or a washing machine. Spinal disorders in the neck can lead to severe shoulder and upper back pain, as well as terrible, nauseating, blinding headaches often misdiagnosed and repeatedly treated as migraines (usually unsuccessfully). This can make simple computer work or talking on the phone continuously very difficult without proper ergonomics.

A key issue in the medical evaluation of spinal disorders is to ascertain whether there is ongoing nerve injury or pressure, as opposed to more musculo-skeletal mechanical pain. Nerve damage usually calls for a more aggressive medical approach. "Pinched nerves" manifest as pain or electrical tingling or numbness or weakness in the arms or legs, depending on the nerve pinched. Spinal cord pressure, when occurring over time as a result of stenosis, can lead to tingling and clumsiness of both hands, balance problems, and spasticity or heaviness of the legs. Acute bowel and bladder dysfunctions are considered spinal emergencies.

Treatment options, coping with pain

Treatments for spinal disorders run the gamut from rest, ice and heat to physical treatments such as physical therapy, chiropractic and massage. There are, of course, the myriad of anti-inflammatory, pain, muscle relaxant and nerve medicines, in addition to all the exercise and complementary care options. Almost any part of the spine can be reached with an injection of medicine or with more intricate catheter devices. And then there is surgery, which either serves to decompress (open up) a tight space or to stabilize a loose disc or joint region. There are now artificial discs for some people who qualify for this option. Being limber, being strong and being of relatively normal body weight with good posture are certainly helpful starting points for everyone.

Generally disc herniations, pinched nerves and muscle strains are problems of 20-to-50-year-olds. Degenerative discs and multiple-level fusion surgeries are problems of people in their 40s and 50s, and severe arthritis and spinal stenosis are problems of those in their 60s or older. These statements are, of course, major generalizations, but when wondering how spine disorders may affect a community of people committed to long term co-existence, awareness of some trends can be enlightening.

Obviously any malady has the capacity to interfere with our schedules, routines or plans, along with our physical and mental states of well-being. Spinal problems mostly affect us through pain, but a significant minority of people are also affected through weakness, loss of normal sensation or loss of basic bodily functions. The challenge of pain is that it is invisible, intimate, intensely personal and subjective. Pain tolerance

The challenge of pain is that it is invisible, intimate, intensely personal and subjective. Pain tolerance is a complex concept going far beyond the technicalities of biology and nerve endings. It is manifested in the context of culture, family history, incentives and disincentives, spiritual motivation, etc.

is a complex concept going far beyond the technicalities of biology and nerve endings. It is manifested in the context of culture, family history, incentives and disincentives, spiritual motivation, etc.

In religious circles, many have been taught the principle of sacrifice and "offering it up" when it comes to pain, disappointment, loss and suffering. In cultural or gender terms, some have been taught to be tough, silent and "take it like a man," while others are used to expressing any type of disease vocally and overtly in order to elicit the care and attention felt to be needed and deserved.

Almost all activities can be better tolerated by changes in position, arrangements of breaks, and alternation of different types of tasks. Medications can provide amazing relief but can be limiting due to their side effects. For example, muscle relaxants can make one drowsy. They are better taken at night. Some strong pain medicines can also make one drowsy, as well as constipated. New medicines are now available to naturally help keep one alert during the day. There are medicines which contain caffeine which can be used during the day, while the more sedating ones can be used at night.

Strong pain medicines, unlike alcohol, which affects

judgment and reaction time, can be used and still allow one to drive. This must be done with caution and with the awareness that one is responsible for one's actions behind the wheel. The longer the list of one's medicines for all one's conditions, the more the possible combined side effects.

Many people worry about becoming addicted to pain medicines. Addiction is often a consequence of a tendency to look for quick fixes, find external solutions to one's problems, and avoid of any sense of pain or even emotional discomfort. Chronic smokers and alcoholics have higher risks of becoming addicted to narcotic (opiate) pain medicines if not watched closely by their physicians. Nearly everyone will become somewhat "physiologically dependent" on opiates if they take

The vocation director might ask an applicant if he or she has tried other forms of pain management apart from drugs. Is the person open to alternatives? Who is monitoring him or her? What are the side effects of the current drug treatment? Evasive answers could indicate a problem.

them for more than a month or two. This just means that one should not stop them "cold turkey" without consulting one's physician and that, over time, one might find that higher doses are needed to maintain pain relief. The physician and patient must maintain mutual close and honest monitoring of such situations. Members of communities must resist the urge to judge another's pain tolerance, while at the same time being responsible in noticing whether a fellow member is becoming too dysfunctional or focused purely on a drug-based approach to pain management.

Vocation directors evaluating a person with spinal problems who uses medication for pain relief might want to discuss these matters in detail. The vocation director might ask an applicant if he or she has tried other forms of pain management apart from drugs. Is the person open to alternatives? Who is monitoring him or her? What side effects does the current drug treatment have? Evasive answers could indicate a problem.

Injections, usually consisting of a steroid type medicine and local anesthetic, can be used to manage spine pain. Epidural steroid injections are most often used for pinched nerves or spinal stenosis. Facet injections are used for arthritis. Muscle trigger point or botox injections are used for chronic muscle or soft tissue pain. Newer heat based treatments for joints and discs can serve to extend the relief obtained when medicine injections are good but not long-lasting. Most spine injections are now done with x-ray (fluoroscopic) guidance, and, if necessary, with some light sedation. Most low back injections are tolerated with just local anesthetic however.

Spine injections can be spaced out every two-to-four months, especially in older people, if that is the medical treatment most effective for a particular person. One can return to regular activity within one day of most spine injections. A younger person cannot plan on using steroid injections every two-to-four months indefinitely and so must seek out other effective alternatives.

Physical and occupational therapy can dramatically impact how much more functional an individual can be through direct pain-relief techniques, coaching on stretches and exercises, and sometimes amazingly simple changes in body mechanics and the use of adaptive devices.

Impact on community and ministry

When people who have spinal problems live in a religious community, the way they handle pain and dysfunction, and the way they express pain and communicate their needs impacts the lives, routines and duties of the rest of the community. Some bear up as soldiers, while others become "lame" and "paralyzed" by sometimes the smallest of discomforts. Vocation ministers would do well to understand where on this continuum a candidate with chronic pain falls. They may become aware of this only by spending time with the prospective member, living and working with the person.

When looking at community life, those with ongoing back pain must be responsible—to some degree—for their duties to others in spite of their own discomforts, while the community is responsible for caring for members who just can't keep up anymore. When individuals carry certain diagnoses, it is helpful to be aware of some of the true, inherent limitations as well as what may allow someone to be more functional in spite of a spinal disorder. For vocation ministers this

means good communication with medical experts is essential.

Living in community requires different people to handle different tasks for the benefit of all. If a person with spinal disorders is responsible for upkeep of a home or landscape, body mechanics and pacing will be key. Those with herniated discs that worsen with bending and lifting probably will have a harder time. Those with stenosis or facet pain can often bend without problems. Those whose jobs or duties require lots of walking or prolonged standing likely will not do well if they have severe spinal stenosis or facet joint arthritis. Those with severe headaches and shoulder pain due to neck problems will probably need breaks from constant computer work or from situations requiring lots of interactions with others in face-to-face contexts and expectations of sustained pleasant moods.

Some may find their pain worst first thing in the morning and may take longer to get “oiled up” and moving, taking pain medicines right out of bed. They need to do a regular stretching routine at night and in the morning and would do well to take a muscle relaxant, pain medicine or anti-inflammatory medicine before going to bed. If sleep is fitful, sometimes antidepressant medicines are very effective for both pain relief and sleep, in addition to decreasing the depression and low energy that comes from chronic pain and poor sleep.

Others get worse as the day goes on and fatigue in their activities and pain tolerance by late morning and again into late afternoon. They must schedule activities in short task formats and use common sense in not overloading themselves with back-to-back commitments. Such self-induced demands will only backfire. They need to do stretches, meditation, centering prayer or stress relief exercises at regular intervals. A brief nap is simple and effective for many.

Time has to be put aside for physical therapy treatments when they are called for. Massage therapy, thought to be a luxury by many, is often a rejuvenating saving hour taken out of one’s schedule every one or two weeks if that is what keeps muscles less achy and stiff.

Acupuncture works for many people, but it is an entire system and approach of care, not merely the one-or-two-session quick fix that we Americans often seek. Chiropractic adjustments are good when this is the modality that provides relief of intermittent acute epi-

sodes of pain or lack of mobility. Long-term weekly into monthly adjustment schedules are, by definition, not really exhibiting lasting effectiveness. One should usually at least seek an evaluation with a spine specialist physician and physical therapist who may design a more active, less passive approach to diagnosing and treating the problem at hand. One should learn as much self-care as possible and beware of any caregiver—physician, physical therapist, chiropractor, acupuncturist—who merely runs on and on with frequent, but ineffective treatment approaches.

There is the very real discernment of determining whether one goes on by just “offering it up.” That is the case when the issue is one of pain, not of neurologic injury in the context of spine disease. Weakness, numbness and loss of coordination, bowel or

Pain, in the end, all too often does have to be borne and suffered, but there are many ways to be assisted in managing pain. Simply “being the martyr” does not really help anyone if one’s behavior also irritates and impacts others in one’s community in a negative way.

bladder function are urgent signals that one needs medical attention. God does not ask us to be foolish in the care of our body temples.

Pain, in the end, all too often does have to be borne and suffered, but there are many ways to be assisted in managing pain. Simply “being the martyr” does not really help anyone if one’s behavior also irritates and impacts others in one’s community in a negative way. Jesus was quite practical in many of his lessons and his actions. We are called to seek out the help and expertise made available to us in the gifts of those around us. God may be asking you to seek out relief so that you can be of better service to others. God asks others to seek you out to help you, and asks you to be open and humble and gracious enough to receive that help.

Despite the wonderful intentions of those who want to live lives of service, sometimes pain interferes too greatly to adequately live such a vocation. Vocation

ministers are called on to wisely assess the capacities of applicants with spinal disorders. It's important to consult with medical professionals to get a full picture of such applicants' abilities, treatment and prognosis. Hopefully this article has served as a primer for vocation ministers to understand chronic back pain and better discern whether an applicant with this condition can contribute and thrive in a religious community. ✚