National Alliance of Methadone Advocates

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Methadone Maintenance and Patient Self-Advocacy

by

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Methadone has allowed me to salvage my life. In May of 1988, following a fourth relapse, my twenty-year marriage, my relationships with my sons, and indeed my very existence was under attack by addiction. Methadone maintenance treatment has granted me the chance to heal myself while repairing shattered relationships. My husband and I are now able to renew our love. My children can again rely upon me, and I have returned to work. Hippocrates said, "Healing is a matter of time, but it is some also a matter of opportunity." The program has given me that opportunity. The siege is over and the healing has begun.

I have been asked to share some thoughts and concerns to many successful methadone maintenance patients, specifically as they relate to that all important decision of whether it's time to advocate for oneself...determining when it is no longer sufficient nor appropriate for Program Administrators and staff members to speak for you...determining when, as a patient, one is capable of coming to terms with the fact that a significant part of recovery is both disclosing who you are and what your require to continue, even when that recovery is methadone maintenance.

Partially because substance abuse professionals within the methadone maintenance field are so very aware of the bigotry confronting the methadone patient, they tend to shield the patient form public scrutiny. Counselors, nurses and other staff members often feel that if they speak on behalf of the methadone patient, indeed if they alleviate the need for the patient to advocate for himself, they then can protect the recovering addict from the invasiveness of outside prejudice. Although selfless in nature, this approach often can extend longer than is healthy for many of us who are well along into our recoveries; or conversely for those who are still struggling with recovery but require a sense of self worth to continue in the day to day work of abstinence. By understanding or sensing that it's "okay to be on methadone," we as recovering addicts, regardless of our stage in sobriety, can in turn send a message through our actions that we are healthy individuals ready to become functioning, contributing citizens.

On a purely selfish level, there are clearly some methadone patients who, if they "come out of the closet" would only serve to further perpetuate harm to an already negative public myth that surrounds methadone clinics and their patients. It is however, the other segment of the patient population that should be addressed and encouraged to take an active role in the consumerism of recovery, particularly as it relates to self-advocacy within their own clinics and with local and state officials. For clearly, when patients are invested in their own treatment, opting responsibility for their own recovery, the results are all the more positive.

Occasionally, in the development f a working self-advocacy program, staff members may feel the impulse to "put the lid on" some seemingly chancy activity because of inherent risk, threat or embarrassment to the Program. This instinct hopefully will be diminished by the knowledge that an essential part of any growth process is the opportunity to make mistakes, benefit from those errors in judgment and go forward. Because methadone patients have relatively low levels of self-confidence and esteem, it may be necessary for program staff members to signal their confidence in and acceptance of the stabilized methadone patient as an individual capable of coming to terms with the issues and stresses of self disclosure and advocacy. Initially, even successful patients may be reluctant to come forward and spread the word of their success on methadone, but with repeated clinic encouragement and preparation, a core group will soon form and attract other stable, sober patients.

As a patient at the Substance Alternative Clinic (SAC) in Nassau County, I have been fortunate to witness and be involved in the growth of our own patient advocacy activities, Within the last year, this group has undertaken numerous endeavors to involve methadone patients at SAC more actively in treatment policy, programming and planning, in public education and in healthy alternative activities in their clinics and communities that not only benefit the individual patients, but their familiar, communities and all methadone patients. Within the clinic, for example, a Patient Advisory Committee was established to work with the SAC Program Director on matters of concern to the patient, community and staff. Suggestion boxes prominently displayed in the units serve as conduits for patient comments and suggestions that are in turn discussed by patient-representatives and the Director. As a result, a myriad of changes have been effected ranging from those of patient's basic dignity to matters of patient convenience. Additionally, selected patients serve with staff to revise clinic policy. The involvement of their peers in administrative policy changes is utilized to allay patient concerns that clinic procedures not be mandated unilaterally without the aid of their fellow patients' collaboration. The anticipated result is an increase in patient acceptance and compliance with clinic regulations. And, a clinic newsletter, now published monthly by patients, reports on clinic activities and serves as an important forum for problems and issues. The newsletter has significantly enhanced communication and understanding by patients of all aspects of the clinic's programs.

Beyond the clinic sphere, public advocacy and education has been a priority. Following the highly slanted "investigative" piece appearing in Newsday this summer, patients wrote letters of protest to editorial staff, and various SAC patient groups wrote letters of concern and protest to public officials regarding ongoing GAO audits of methadone clinics. An important item of note is that several active members have begun, in their strong belief in the positive powers of methadone maintenance, to utilize both their first and last names when identifying themselves as methadone patients - indicative that anonymity is secondary in importance to crucial matters of advocacy.

In August 1989, Nassau County's newly appointed Director of Drug Enforcement/Information Council attended the Friday Night Peer Support Group at SAC as an honored guest and speaker. The Group was able to alert the Director to the critical need for the education of the county's judicial and penal system officials in order to debunk the myths and legends that have continually surrounded methadone maintenance treatment programs. By meeting's end, an empathy and deeper understanding by the Drug Enforcement Director was perceived which further reinforced the self-advocacy theorem as well as advanced the patients' self esteem and confidence, providing the impetus to go further.

Additional SAC activities have been initiated and while not specifically advocacy oriented, have directly linked many patients to healthy, "straight" activities and relationships - in many cases for the first time in years. In May, the SAC Mother's Group sponsored the first in a series of clinic bake sales to benefit clinic children's activities. Initiated and run entirely by volunteer patients, the success of the sale sent a clear message that many patients were no longer solely content to just report to their clinic for

medication, and that involvement in clinic events and advocacy was involvement in one's own recovery. October marked the opening of a patient-run and patient-donated SAC Clothing Swap shop to supply any patient or family member in need with used presentable warm garments.

There is little question that it may initially require a "leap of faith" for clinic administrators and staffers to promote and encourage patient self-advocacy. Staff may be discomforted at first, unsure that the patients may say something out of line, that some power has been transferred or lost, and roles and identities blurred. Coupled with the need to "let go" staff must also be alert to patient disappointments and discouragements. Patients may tend, in their new found zeal, to take on everything and everybody, in an attempt to prove that their recovery is here to stay as well as powerful. But clearly the risks bring rewards. Patients will unite, networking together to both protect their program as well as expand their horizons into the community with the message that methadone maintenance is an important, positive recovery tool.

Notably, with entrance into public activism, comes the patient's greater awareness of himself as an enfranchised individual; someone with the rights and power of the voting booth. With the realization comes power...power to effect change as a member of a constituency that verbalizes how they wish the localities' scarce funds expended in the arena of drug addiction...power to remove officials from office if they are not responsive to the requirements of the patient activist.

Methadone maintenance treatment, always controversial, has recently attracted another spate of unwarranted, negative attention. Federal and State audit-investigations abound...seemingly convinced from their inception that methadone treatment is equivalent to the continuation of an addict's active addiction, not necessarily supportive of abstinence nor a "true" recovery program. Given the less than enthusiastic reception of methadone as a treatment modality by elected officials and the misperceptions of the general populace, continuing existence and growth of patient self-advocacy groups is essential. Inherent in the validation of methadone treatment as a recovery tool is communication and cohesiveness between clinic staff and stabilized patients who are prepared to be advocates. It's time to take the burden off the shoulders of clinic personnel and share it with those who are the only ones in a position to speak personally of the struggle as well as the joys of methadone maintenance treatment and recovery.

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