

White Paper for Treatment Options for Chronic Complex Illness

What follows is a document that any patient, parent, or caregiver can provide to their medical team seeking to deal with complex chronic medical illness. It also defines what an informed consent is and the mission statement of the International Lyme and Associated Disease Society (ILADS).

Purpose of this document:

It is important that a mutual relationship between the treating medical provider and patient, be built on trust, honesty, respect, and understanding while establishing an informed consent. Information should be discussed with the patient and / or guardians, so he/she/they can make an educated decision of receiving/not receiving a treatment under the current standards of care with a tick- bite.

Informed Consent:

Evidenced-based medicine dogma asserts that patient preference must be incorporated in the calculus of benefit and harm, because benefit and harm are relative and judged by the subject - the patient. Full, complete, and unbiased informed consent is a legal and ethical obligation. These are core legal and ethical tenets that are often ignored in medical policymaking. These principles fueled by our empathy for those who suffer will continue to drive us collectively. There are certain core tenets in medicine. It is well known by doctors, but, too often, not by patients, the doctor-patient relationship is governed by trust, but also by obligations of medical professionals. Among those obligations are the ethical, legal, and medical requirement that the doctor inform the patient about possible treatment(s). This is covered by the Doctrine of Informed Consent.

The code of ethics is built around insuring that both patients and doctors participate meaningfully in medical decisions about healthcare. Physicians have a responsibility to provide information that helps patients understand their medical condition and their options for treatment. This is the doctrine of informed consent. In fact, doctors must ensure that patients are told of their diagnosis, that patients understand the nature and purpose of recommended interventions, and most importantly, that patients are made aware of the benefits, risks, and burdens of any option(s).

The American Medical Association (AMA) states: "to enable patients to participate meaningfully about their healthcare, physicians have a responsibility to provide information and help their medical condition and options for treatment...informed consent to medical treatment is fundamental to ethics and law. It helps patients make well considered decisions about their care and treatment".

ILADS (International Lyme & Associated Diseases Society) Mission Statement:

ILADS is a nonprofit, international, multidisciplinary medical society dedicated to the appropriate diagnosis and treatment of Lyme and associated diseases. ILADS promotes understanding of Lyme and associated diseases through research, education and policy. We strongly support physicians, scientists, researchers and other healthcare professionals dedicated to advancing the standard of care for Lyme and associated diseases.

Complex Chronic Illness Treatment Options:

The patient understands that there are multiple recommended options for treatment of a complex chronic illness. The current healthcare provider has been working on implementing strategies for care to address many of these issues. If this white paper is being presented, this means that the patient has an urgent, emergent, acute need or has been referred to a sub-specialist to address a condition that is either a consequence of the complex illness, its treatment, or a co-morbidity requiring additional care.

The patient understands that there are possible benefits and risks of ongoing foundational treatment. These have already been covered by the healthcare provider who provided the ongoing treatment regimen and this white paper. The diagnoses / problem list of this patient by this healthcare provider include(s):

The healthcare provider who is providing this information recommends that the following treatments be continued during acute care, hospitalization and / or sub-specialty care in order to maintain the best long-term plan of care for the patient:

ILADS believes that the best possible care is decided among the medical care team and the patient and this document serves to facilitate that type of communication.

The healthcare provider who is providing this white paper is:

Healthcare Provider

Office Phone Number

Further communication is encouraged if needed to benefit the patient or to learn more about the treatment of the chronic, complex illness that is part of this patient's pertinent medical history.

INFORMED CONSENT:

I, _____, am a patient receiving treatment at present for complex illness and respectfully request that my current medical care team or sub-specialist utilize the information provided above, along with my personal preferences, in order to treat me for the condition for which I am being seen. I understand that different healthcare providers, different specialties, and different healthcare settings may not provide the same types of interventions, and this document serves to communicate that I wish to continue to receive ongoing care that is listed above while in an acute care setting, while hospitalized, or while getting care from a sub-specialist.

Signature of Patient / Guardian / Parent

Date

Signature of Second Parent (for minors)

Date

Signature of Attending Health Care Provider

Date

Note: The signature of both parents is required for minors if a medication is being prescribed, unless the parent has written proof of sole custody for the minor receiving medical attention.