

Social media and Communication Examples for Family Centered-Care Advisors

<i>If connection with the other family is...</i>	Example: Not OK	Example: OK
In or because of the FCC advisor role		
No social media including Facebook, Caring Bridge, Twitter or similar <ul style="list-style-type: none"> No friending, messaging, posting on wall 		“I am so glad to hear from you. Because of my role as a volunteer, I am not permitted to friend on social media sites. Wishing you and your family all the best”
No reaching out to communicate with patient family <ul style="list-style-type: none"> No emailing or giving private email address, no telephoning, no texting 	Met another parent while in the Parent Ambassador role, then find out your children go to school together (except you may communicate separately about school events) Learned of a parent who filed a grievance and FCC advisor approaches to discuss FCC	OK only if it is a specific part of your role as an advisor, i.e., PAIR mentor <ul style="list-style-type: none"> Must use St. Jude email account or SJ issued devices Response to someone reaching out: “I am so glad to hear from you. Because of my role as a volunteer, I am not permitted to email/text/phone call with families. Wishing you and your family all the best.”
Limited communication regarding St. Jude business (No PHI) with other FCC advisors and SJ employees <ul style="list-style-type: none"> No using social media sites Email and calling ok (Be mindful of privacy and security issues) 	Discussing PHI	Updates regarding FCC business topics Recruitment of parent for FCC adviser role Prefer use of St. Jude email account if one has been provided; otherwise, must use password protection on personal devices such as phones and laptop
Outside of the FCC advisor role	Example: Not OK	Example: OK
Social media communications permitted if neither PHI nor St. Jude affiliation is mentioned <ul style="list-style-type: none"> OK to friend, message, post, OK to call, email Note that mental health, HIV status, drug abuse and certain sensitive information is particularly protected under the law 	Discussing PHI or St. Jude affiliation <ul style="list-style-type: none"> So glad you son’s AML is better. See you next time you’re at St. Jude So glad SJ cured your child’s disease When was he diagnosed? Who is your doctor? Is she taking xyz medication? Meet you at Kay Kafe next time! I’m sorry she has to go for proton therapy. Did you hear about the shortage of the drug your child is taking? Post gives medically bad news. Response: Did you know that 20% of patients with his diagnosis have that outcome? 	<ul style="list-style-type: none"> Very generic responses to posts Prefer password protection on personal devices such as phones and laptops Post is “No more chemo!” OK Response: That’s great! Congrats, way to go! Post gives medically bad news OK Response: I’m so sorry. Best to you and your family. We’re praying for you. Post gives news of patient death. OK Response: Condolences, offers to help and/or pray, inquiries about funeral arrangements, donations.

The legal and policy considerations that inform these rules are:

Respect and appreciation for the role and relationship of parents and the importance of their supporting each other through difficult and good times;
 HIPAA and state laws requiring strict protection of the privacy of patient data;

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HIPAA law requiring appropriate safeguards of PHI to protect it from being viewed if device is lost or email account is hacked;
The need to guard the confidentiality of St. Jude operations and decision-making information with which you are entrusted;
Protection of professional boundaries between workforce members (which, under HIPAA, includes volunteers) and patients/families.