

LONG-TERM CARE MAP FOR SPINA BIFIDA
Spina Bifida ONLY
Spina Bifida with Shunt in place

AGE	ACTION/INTERVENTION	RESPONSIBLE PERSON	OUTCOME
NEWBORN	1) Assessment - born at Scott and White. 2) Neurosurgical intervention - myelomeningocele repair, shunt placement. 3) Urological intervention. 4) Texas Health Steps/newborn-follow-up-born at Scott and White. 5) Texas Health Steps/1-2 weeks follow-up. 6) Assessment - NOT born at Scott and White.	1) Neonatologist, Team Coordinator, Social Worker (consults may be made to Neurosurgery, Urology, or other disciplines as needed). 2) Nurse, Neurosurgeon, Neonatologist/Pediatrician. 3) Urologist, Nurse. 4) PCP/Pediatrician, Nurse. 5) PCP/Pediatrician, Nurse. 6) Referral from PCP/Pediatrician to Spina Bifida Team (contact person: Team Coordinator).	1) Communication/information about diagnosis and financial assistance. 2) Neurosurgeon follow-up, suture and wound care instructions. 3) Information/treatment regarding bowel & bladder care. 4) Surgery care follow-up. 5) Routine follow-up, well baby check, establish care with PCP/Pediatrician. 6) Schedule pre-team assessment appointments.
6 WEEKS	1) Neurosurgery follow-up.	1) Neurosurgeon, Nurse.	1) Check-up with information regarding continued care specific to individual patient.
2 MONTHS	1) Texas Health Steps/2 month medical follow-up.	1) PCP/Pediatrician, Nurse.	1) Well baby check.
3-6 MONTHS	1) Urology follow-up.	1) Urologist, Nurse.	1) Check-up with information regarding continued care specific to individual patient with minimal annual follow-ups scheduled.
4 MONTHS	1) Texas Health Steps/4 month medical follow-up. 2) Medical record review.	1) PCP/Pediatrician, Nurse. 2) Team Coordinator.	1) Well baby check. 2) Tracking/monitoring.

6 MONTHS	1) Texas Health Steps/6 month medical follow-up. 2) Medical record review.	1) PCP/Pediatrician, Nurse. 2) Team Coordinator.	1) Well baby check. 2) Tracking/monitoring.
9 MONTHS	1) Texas Health Steps/9 month medical follow-up. 2) Medical record review.	1) PCP/Pediatrician, Nurse. 2) Team Coordinator.	1) Well baby check. 2) Tracking/monitoring.
12 MONTHS/1 YEAR	1) Texas Health Steps/1 year medical follow-up. Establish dental care. 2) Medical record review.	1) PCP/Pediatrician, Nurse, Dentist/Hygienist. 2) Team Coordinator.	1) Well baby check. Establish dental care. 2) Tracking/monitoring.
1-3 YEARS	1) Team visits begin. Family completes Needs & Concerns form & Information Questionnaire/Update.	1) Orthopedics, Pedi-Neurology, Pedi-GI, PM&R, Physical Therapy, Team Coordinator (referrals as needed).	1) Establishment of the Comprehensive Treatment Plan. Review Needs & Concerns form & Information Questionnaire/Update. Schedule therapy treatment & follow-up visits as discussed with family.
1-20 YEARS	1) Possible treatment interventions may include stretching program, heel cord lengthening, bracing, nutritional evaluation & rehabilitation, as clinically indicated, neuroimaging until after puberty, etc. 2) Additional referrals as needed for vision/hearing exams.	1) Orthopedics, Pedi-GI, Pedi-Neurology, PM&R, Physical Therapy, and/or referrals to other disciplines as needed per diagnosis. 2) Referral by PCP / Pediatrician to Ophthalmologist and/or Audiologist as needed.	1) Schedule corrective therapies, appointments and/or equipment needs. 2) Follow-up by Ophthalmologist and/or Audiologist at least annually unless otherwise specified.
18 MONTHS	1) Texas Health Steps/dental. 2) Annual Urology follow-up. 3) Medical record review.	1) Dentist/Hygienist. 2) Urologist, Nurse. 3) Team Coordinator.	1) Dental check. 2) Urological check-up, patient supply update. 3) Tracking/monitoring.
2 YEARS/24 MONTHS	1) Texas Health Steps/medical and dental follow-up. 2) Medical record review.	1) PCP/Pediatrician, Nurse, Dentist/Hygienist. 2) Team Coordinator.	1) Well child check. Dental check. 2) Tracking/monitoring.

2 ½ YEARS/30 MONTHS	<p>1) Texas Health Steps/dental.</p> <p>2) Annual Urology follow-up.</p> <p>3) Medical record review.</p>	<p>1) Dentist/Hygienist.</p> <p>2) Urologist, Nurse.</p> <p>3) Team Coordinator.</p>	<p>1) Dental check.</p> <p>2) Urological check-up, patient supply update.</p> <p>3) Tracking/monitoring.</p>
3 YEARS/36 MONTHS	<p>1) Annual team visit. Family completes Needs & Concerns form & Information Questionnaire/Update.</p> <p>2) Texas Health Steps/medical and dental follow-up.</p> <p>3) Medical record review.</p>	<p>1) Orthopedics, Pedi-Neurology, Pedi-GI, PM&R, Physical Therapy, Team Coordinator (referrals as needed).</p> <p>2) PCP/Pediatrician, Nurse, Dentist/Hygienist.</p> <p>3) Team Coordinator.</p>	<p>1) Establish Comprehensive Treatment Plan. Review Needs & Concerns form & Information Questionnaire/Update. Schedule therapy treatment follow-up visits as discussed with family.</p> <p>2) Well child check. Dental check.</p> <p>3) Tracking/monitoring.</p>
3 ½ YEARS/42 MONTHS	<p>1) Texas Health Steps/dental.</p> <p>2) Annual Urology follow-up.</p> <p>3) Medical record review.</p>	<p>1) Dentist/Hygienist.</p> <p>2) Urologist, Nurse.</p> <p>3) Team Coordinator.</p>	<p>1) Dental check.</p> <p>2) Urological check-up, patient supply update.</p> <p>3) Tracking/monitoring.</p>
4 YEARS	<p>1) Annual team visit. Family completes Needs & Concerns form & Information Questionnaire/Update.</p> <p>2) Texas Health Steps/medical and dental follow-up.</p> <p>3) Medical record review.</p>	<p>1) Orthopedics, Pedi-Neurology, Pedi-GI, PM&R, Physical Therapy, Team Coordinator (referrals as needed).</p> <p>2) PCP/Pediatrician, Nurse, Dentist/Hygienist.</p> <p>3) Team Coordinator.</p>	<p>1) Establishment of the Comprehensive Treatment Plan. Review Needs & Concerns form & Information Questionnaire/Update. Schedule therapy treatment & follow-up visits as discussed with family.</p> <p>2) Well child check. Dental check.</p> <p>3) Tracking/monitoring.</p>
4 ½ YEARS	<p>1) Texas Health Steps/dental.</p> <p>2) Annual Urology follow-up.</p> <p>3) Medical record review.</p>	<p>1) Dentist/Hygienist.</p> <p>2) Urologist, Nurse.</p> <p>3) Team Coordinator.</p>	<p>1) Dental check.</p> <p>2) Urological check-up, patient supply update.</p> <p>3) Tracking/monitoring.</p>

5 YEARS	<p>1) Annual team visit. Family completes Needs & Concerns form & Information Questionnaire/Update.</p> <p>2) Texas Health Steps/medical and dental follow-up.</p> <p>3) Medical record review.</p>	<p>1) Orthopedics, Pedi-Neurology, Pedi-GI, PM&R, Physical Therapy, Team Coordinator (referrals as needed).</p> <p>2) PCP/Pediatrician, Nurse, Dentist/Hygienist.</p> <p>3) Team Coordinator.</p>	<p>1) Establishment of the Comprehensive Treatment Plan. Review Needs & Concerns form & Information Questionnaire/Update. Schedule therapy treatment & follow-up visits as discussed with family.</p> <p>2) Well child check. Dental check.</p> <p>3) Tracking/monitoring.</p>
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6 YEARS	<p>1) Annual team visit. Family completes Needs & Concerns form & Information Questionnaire/Update.</p> <p>2) Texas Health Steps/medical and dental follow-up.</p> <p>3) Medical record review.</p>	<p>1) Orthopedics, Pedi-Neurology, Pedi-GI, PM&R, Physical Therapy, Team Coordinator (referrals as needed).</p> <p>2) PCP/ Pediatrician, Nurse, Dentist/Hygienist.</p> <p>3) Team Coordinator.</p>	<p>1) Establishment of the Comprehensive Treatment Plan. Review Needs & Concerns form & Information Questionnaire/Update. Schedule therapy treatment & follow-up visits as discussed with family.</p> <p>2) Well child check. Dental check.</p> <p>3) Tracking/monitoring.</p>
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7 YEARS	<p>1) Annual team visit. Family completes Needs & Concerns form & Information Questionnaire/Update.</p> <p>2) Texas Health Steps/medical and dental follow-up.</p> <p>3) Medical record review.</p>	<p>1) Orthopedics, Pedi-Neurology, Pedi-GI, PM&R, Physical Therapy, Team Coordinator (referrals as needed).</p> <p>2) PCP/Pediatrician, Nurse, Dentist/Hygienist.</p> <p>3) Team Coordinator.</p>	<p>1) Establishment of the Comprehensive Treatment Plan. Review Needs & Concerns form & Information Questionnaire/Update. Schedule therapy treatment & follow-up visits as discussed with family.</p> <p>2) Well child check. Dental check.</p> <p>3) Tracking/monitoring.</p>

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8 YEARS	<p>1) Annual team visit. Family completes Needs & Concerns form & Information Questionnaire/Update.</p> <p>2) Texas Health Steps/medical and dental follow-up.</p> <p>3) Medical record review.</p>	<p>1) Orthopedics, Pedi-Neurology, Pedi-GI, PM&R, Physical Therapy, Team Coordinator (referrals as needed).</p> <p>2) PCP/Pediatrician, Nurse, Dentist/Hygienist.</p> <p>3) Team Coordinator.</p>	<p>1) Establishment of the Comprehensive Treatment Plan. Review Needs & Concerns form & Information Questionnaire/Update. Schedule therapy treatment & follow-up visits as discussed with family.</p> <p>2) Well child check. Dental check.</p> <p>3) Tracking/monitoring.</p>
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9 YEARS	<p>1) Annual team visit. Family completes Needs & Concerns form & Information Questionnaire/Update.</p> <p>2) Texas Health Steps/medical and dental follow-up.</p> <p>3) Medical record review.</p>	<p>1) Orthopedics, Pedi-Neurology, Pedi-GI, PM&R, Physical Therapy, Team Coordinator (referrals as needed).</p> <p>2) PCP/Pediatrician, Nurse, Dentist/Hygienist.</p> <p>3) Team Coordinator.</p>	<p>1) Establishment of the Comprehensive Treatment Plan. Review Needs & Concerns form & Information Questionnaire/Update. Schedule therapy treatment & follow-up visits as discussed with family.</p> <p>2) Well child check. Dental check.</p> <p>3) Tracking/monitoring.</p>
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10 YEARS	<p>1) Annual team visit. Family completes Needs & Concerns form & Information Questionnaire/Update.</p> <p>2) Texas Health Steps/medical and dental follow-up.</p> <p>3) Medical record review.</p>	<p>1) Orthopedics, Pedi-Neurology, Pedi-GI, PM&R, Physical Therapy, Team Coordinator (referrals as needed).</p> <p>2) PCP/Pediatrician, Nurse, Dentist/Hygienist.</p> <p>3) Team Coordinator.</p>	<p>1) Establishment of the Comprehensive Treatment Plan. Review Needs & Concerns form & Information Questionnaire/Update. Schedule therapy treatment & follow-up visits as discussed with family.</p> <p>2) Well child check. Dental check.</p> <p>3) Tracking/monitoring.</p>
10 ½ YEARS	<p>1) Texas Health Steps/dental.</p> <p>2) Annual Urology follow-up.</p> <p>3) Medical record review.</p>	<p>1) Dentist/Hygienist.</p> <p>2) Urologist, Nurse.</p> <p>3) Team Coordinator.</p>	<p>1) Dental check.</p> <p>2) Urological check-up, patient supply update.</p> <p>3) Tracking/monitoring.</p>
11 YEARS	<p>1) Annual team visit. Family completes Needs & Concerns form & Information Questionnaire/Update.</p> <p>2) Texas Health Steps/medical and dental follow-up.</p> <p>3) Medical record review.</p>	<p>1) Orthopedics, Pedi-Neurology, Pedi-GI, PM&R, Physical Therapy, Team Coordinator (referrals as needed).</p> <p>2) PCP/Pediatrician, Nurse, Dentist/Hygienist.</p> <p>3) Team Coordinator.</p>	<p>1) Establishment of the Comprehensive Treatment Plan. Review Needs & Concerns form & Information Questionnaire/Update. Schedule therapy treatment & follow-up visits as discussed with family.</p> <p>2) Well child check. Dental check.</p> <p>3) Tracking/monitoring.</p>
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12 YEARS	<p>1) Annual team visit. Family completes Needs & Concerns form & Information Questionnaire/Update.</p> <p>2) Texas Health Steps/medical and dental follow-up.</p> <p>3) Medical record review.</p>	<p>1) Orthopedics, Pedi-Neurology, Pedi-GI, PM&R, Physical Therapy, Team Coordinator (referrals as needed).</p> <p>2) PCP/Pediatrician, Nurse, Dentist/Hygienist.</p> <p>3) Team Coordinator.</p>	<p>1) Establishment of the Comprehensive Treatment Plan. Review Needs & Concerns form & Information Questionnaire/Update. Schedule therapy treatment & follow-up visits as discussed with family.</p> <p>2) Well child check. Dental check.</p> <p>3) Tracking/monitoring.</p>

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13 YEARS	<p>1) Annual team visit. Family completes Needs & Concerns form & Information Questionnaire/Update.</p> <p>2) Texas Health Steps/medical and dental follow-up.</p> <p>3) Medical record review.</p>	<p>1) Orthopedics, Pedi-Neurology, Pedi-GI, PM&R, Physical Therapy, Team Coordinator (referrals as needed).</p> <p>2) PCP/Pediatrician, Nurse, Dentist/Hygienist.</p> <p>3) Team Coordinator.</p>	<p>1) Establishment of the Comprehensive Treatment Plan. Review Needs & Concerns form & Information Questionnaire/Update. Schedule therapy treatment & follow-up visits as discussed with family.</p> <p>2) Well child check. Dental check.</p> <p>3) Tracking/monitoring.</p>
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14 YEARS	<p>1) Annual team visit. Family completes Needs & Concerns form & Information Questionnaire/update.</p> <p>2) Texas Health Steps/medical and dental follow-up.</p> <p>3) Medical record review.</p>	<p>1) Orthopedics, Pedi-Neurology, Pedi-GI, PM&R, Physical Therapy, Team Coordinator (referrals as needed).</p> <p>2) PCP/Pediatrician, Nurse, Dentist/Hygienist.</p> <p>3) Team Coordinator.</p>	<p>1) Establishment of the Comprehensive Treatment Plan. Review Needs & Concerns form & Information Questionnaire/Update. Schedule therapy treatment & follow-up visits as discussed with family.</p> <p>2) Well child check. Dental check.</p> <p>3) Tracking/monitoring.</p>
14 ½ YEARS	<p>1) Texas Health Steps/dental.</p> <p>2) Annual Urology follow-up.</p> <p>3) Medical record review.</p>	<p>1) Dentist/Hygienist.</p> <p>2) Urologist, Nurse.</p> <p>3) Team Coordinator.</p>	<p>1) Dental check.</p> <p>2) Urological check-up, patient supply update.</p> <p>3) Tracking/monitoring.</p>

15 YEARS	<p>1) Annual team visit. Family completes Needs & Concerns form & Information Questionnaire/Update.</p> <p>2) Texas Health Steps/medical and dental follow-up.</p> <p>3) Medical record review.</p>	<p>1) Orthopedics, Pedi-Neurology, Pedi-GI, PM&R, Physical Therapy, Team Coordinator (referrals as needed).</p> <p>2) PCP/Pediatrician, Nurse, Dentist/Hygienist.</p> <p>3) Team Coordinator.</p>	<p>1) Establishment of the Comprehensive Treatment Plan. Review Needs & Concerns form & Information Questionnaire/Update. Schedule therapy treatment & follow-up visits as discussed with family.</p> <p>2) Well child check. Dental check.</p> <p>3) Tracking/monitoring.</p>
15 ½ YEARS	<p>1) Texas Health Steps/dental.</p> <p>2) Annual Urology follow-up.</p> <p>3) Medical record review.</p>	<p>1) Dentist/Hygienist.</p> <p>2) Urologist, Nurse.</p> <p>3) Team Coordinator.</p>	<p>1) Dental check.</p> <p>2) Urological check-up, patient supply update.</p> <p>3) Tracking/monitoring.</p>
16 YEARS	<p>1) Annual team visit. Family completes Needs & Concerns form & Information Questionnaire/Update.</p> <p>2) Texas Health Steps/medical and dental follow-up.</p> <p>3) Medical record review.</p>	<p>1) Orthopedics, Pedi-Neurology, Pedi-GI, PM&R, Physical Therapy, Team Coordinator (referrals as needed).</p> <p>2) PCP/Pediatrician, Nurse, Dentist/Hygienist.</p> <p>3) Team Coordinator.</p>	<p>1) Establishment of the Comprehensive Treatment Plan. Review Needs & Concerns form & Information Questionnaire/Update. Schedule therapy treatment & follow-up visits as discussed with family.</p> <p>2) Well child check. Dental check.</p> <p>3) Tracking/monitoring.</p>
16 ½ YEARS	<p>1) Texas Health Steps/dental.</p> <p>2) Annual Urology follow-up.</p> <p>3) Medical record review.</p>	<p>1) Dentist/Hygienist.</p> <p>2) Urologist, Nurse.</p> <p>3) Team Coordinator.</p>	<p>1) Dental check.</p> <p>2) Urological check-up, patient supply update.</p> <p>3) Tracking/monitoring.</p>
17 YEARS	<p>1) Annual team visit. Family completes Needs & Concerns form & Information Questionnaire/Update.</p> <p>2) Texas Health Steps/medical and dental follow-up.</p> <p>3) Medical record review.</p>	<p>1) Orthopedics, Pedi-Neurology, Pedi-GI, PM&R, Physical Therapy, Team Coordinator (referrals as needed).</p> <p>2) PCP/Pediatrician, Nurse, Dentist/Hygienist.</p> <p>3) Team Coordinator.</p>	<p>1) Establishment of the Comprehensive Treatment Plan. Review Needs & Concerns form & Information Questionnaire/Update. Schedule therapy treatment & follow-up visits as discussed with family.</p> <p>2) Well child check. Dental check.</p> <p>3) Tracking/monitoring.</p>

17 ½ YEARS	<p>1) Texas Health Steps/dental.</p> <p>2) Annual Urology follow-up.</p> <p>3) Medical record review.</p>	<p>1) Dentist/Hygienist.</p> <p>2) Urologist, Nurse.</p> <p>3) Team Coordinator.</p>	<p>1) Dental check.</p> <p>2) Urological check-up, patient supply update.</p> <p>3) Tracking/monitoring.</p>
18 YEARS	<p>1) Annual team visit. Family completes Needs & Concerns form & Information Questionnaire/Update.</p> <p>2) Texas Health Steps/medical and dental follow-up.</p> <p>3) Medical record review.</p>	<p>1) Orthopedics, Pedi-Neurology, Pedi-GI, PM&R, Physical Therapy, Team Coordinator (referrals as needed).</p> <p>2) PCP/Pediatrician, Nurse, Dentist/Hygienist.</p> <p>3) Team Coordinator.</p>	<p>1) Establishment of the Comprehensive Treatment Plan. Review Needs & Concerns form & Information Questionnaire/Update. Schedule therapy treatment & follow-up visits as discussed with family.</p> <p>2) Well child check. Dental check.</p> <p>3) Tracking/monitoring.</p>
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19 YEARS	<p>1) Annual team visit. Family completes Needs & Concerns form & Information Questionnaire/Update.</p> <p>2) Texas Health Steps/medical and dental follow-up.</p> <p>3) Medical record review.</p>	<p>1) Orthopedics, Pedi-Neurology, Pedi-GI, PM&R, Physical Therapy, Team Coordinator (referrals as needed).</p> <p>2) PCP/Pediatrician, Nurse, Dentist/Hygienist.</p> <p>3) Team Coordinator.</p>	<p>1) Establishment of the Comprehensive Treatment Plan. Review Needs & Concerns form & Information Questionnaire/Update. Schedule therapy treatment & follow-up visits as discussed with family.</p> <p>2) Well child check. Dental check.</p> <p>3) Tracking/monitoring.</p>
19 ½ YEARS	<p>1) Texas Health Steps/dental.</p> <p>2) Annual Urology follow-up.</p> <p>3) Medical record review.</p>	<p>1) Dentist/Hygienist.</p> <p>2) Urologist, Nurse.</p> <p>3) Team Coordinator.</p>	<p>1) Dental check.</p> <p>2) Urological check-up, patient supply update.</p> <p>3) Tracking/monitoring.</p>

<p>20 YEARS</p>	<p>1) Annual team visit. Family completes Needs & Concerns form & Information Questionnaire/Update. Discuss transition to adult services.</p> <p>2) Texas Health Steps/medical and dental follow-up.</p> <p>3) Medical record review.</p>	<p>1) Orthopedics, Pedi-Neurology, Pedi-GI, PM&R, Physical Therapy, Team Coordinator (referrals as needed).</p> <p>2) PCP/Pediatrician, Nurse, Dentist/Hygienist.</p> <p>3) Team Coordinator.</p>	<p>1) Establishment of the Comprehensive Treatment Plan. Review Needs & Concerns form & Information Questionnaire/Update. Schedule therapy treatment & follow-up visits as discussed with family.</p> <p>2) Well child check. Dental check.</p> <p>3) Tracking/monitoring.</p>
<p>20 ½ YEARS</p>	<p>1) Texas Health Steps/dental.</p> <p>2) Annual Urology follow-up.</p> <p>3) Medical record review.</p>	<p>1) Dentist/Hygienist.</p> <p>2) Urologist, Nurse.</p> <p>3) Team Coordinator.</p>	<p>1) Dental check.</p> <p>2) Urological check-up, patient supply update.</p> <p>3) Tracking/monitoring.</p>
<p>1-21 YEARS</p> <p>Final team visit occurs anytime a patient no longer requires services from ALL of the Spina Bifida Team Specialists.</p>	<p>1) Final team visit. Family completes Needs & Concerns form & Information Questionnaire/Update. Discuss transition from Team to independent pediatric or adult services as age appropriate.</p> <p>2) Texas Health Steps/medical and dental follow-up.</p> <p>3) Medical record review.</p>	<p>1) Orthopedics, Pedi-Neurology, Pedi-GI, PM&R, Physical Therapy, Team Coordinator (referrals as needed).</p> <p>2) PCP/Pediatrician, Nurse, Dentist/Hygienist.</p> <p>3) Team Coordinator.</p>	<p>1) Establish Comprehensive Treatment Plan. Dismiss from team. Transition/refer to age appropriate independent pediatric or adult services.</p> <p>2) Medical check. Dental check.</p> <p>3) Transition tracking/monitoring.</p>
<p>1-21 YEARS</p>	<p>1) The following may also lead to dismissal from the team:</p> <ul style="list-style-type: none"> a) Failure to follow plan of care. b) Consistently not keeping Team Day Clinic appointments. c) Consistently not keeping appointments with individual specialists. 	<p>1) Team specialists, other physicians, Team Coordinator.</p>	<p>1) Assistance with transition to independent physicians or specialists.</p>